

Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study
Focusing on the Transition from Elementary to Secondary School

Marion Edna Trent-Kratz, B.A., B.Ed., B.A., B.A.

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Faculty of Social Sciences, Brock University
St. Catharines, Ontario

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Abstract

Transitioning from elementary to secondary school is a major event in adolescents' lives and can be associated with academic, social, and emotional challenges (Shaffer, 2005; Sirsch, 2003). Considerably less research has focused on the transitional experiences of students with intellectual disabilities (ID) as they enter secondary school and the role of educational inclusion in this process (Noland, Cason, & Lincoln, 2007). Conceivably, students with ID who leave inclusive elementary schools, where they have been educated alongside their peers without ID, and who enter segregated secondary educational placements may experience unique social and emotional challenges (Farmer, Pearl, & Van Acker, 1996; Fryxell & Kennedy, 1995; Shaffer, 2005). This study examined the transitional experiences of 6 students with ID and the role of educational inclusion, with a focus on elementary to secondary school transitions from inclusive to segregated settings and vice versa. This study included the collection of multiple sources of data. Semi-structured interviews with 6 caregivers and students with ID were conducted. Students' Individual Education Transitional Plans were discussed in caregivers' interviews to determine how they shaped students' educational inclusion experiences (Ontario Ministry of Education & Training, 1999/2000/2004). Parts of the following questionnaires were "qualitized" (Tashakkori & Teddlie, 1998) and administered orally: "Youth Self-Report" (YSR; Achenbach, 2001c) and "Child Behaviour Checklist Caregivers Form" (CBLC/6-18; Achenbach, 2001a). The findings of this study contribute to the literature on educational inclusion by highlighting the positive/negative social and emotional impact of congruent and incongruent transitional experiences of students with ID and the role of educational inclusion.

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Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study
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Chapter 1

Introduction

The transition from elementary to secondary school is a major event in all students' lives, including students with disabilities (Gillison, Standage, & Skevington, 2008; Newman, Newman, Griffen, O'Connor, & Spas, 2007; Noland et al., 2007; Rudolph, Lambert, Clark, & Kurlakowsky, 2001; Sabbatino & Macrine, 2007; Siedman, Allen, Aber, Mitchell, & Feinman, 1994; Sirsch, 2003; Smith, Akos, Lim, & Wiley, 2008). Students entering secondary school need to adjust to a larger educational environment while adhering to new rules and regulations. Students also need to adjust to the change in the number of teachers and support staff they will encounter, while realizing that their relationships with teachers in secondary school will differ substantially from those they experienced in elementary school. A larger educational environment is often associated with a larger peer group that requires students to reorganize their social roles to be able to gain peer support and a sense of educational belonging in their new schools (Farmer et al., 1996). For the most part, research has shown that transitional experiences of students without ID are positive; however, researchers have found that during the transition to secondary school some students may experience social, emotional, and academic challenges while adjusting to their new schools and peers (Gillison et al., 2008; Newman et al., 2007; Siedman et al., 1994, Sirsch, 2003; Smith et al., 2008). For some students, poor attendance, lower grades, maladaptive behaviours (e.g., substance abuse, criminal activities), and feelings of isolation or social rejection can be associated with the transition from elementary to secondary school (Gillison et al., 2008; Newman et al., 2007). Nevertheless, few researchers have focused

specifically on the social, emotional and academic impact of transitional experiences among students with ID and the role of educational inclusion in this process.

The educational inclusion of students with various disabilities in Ontario's secondary schools has increased substantially over the past decade (Bernard et al., 2005; Ontario Ministry of Education & Training, 1996/2001; Thousand & Rosenberg, 1997; UNESCO, 2003; Weber & Bennett, 2004). Educational inclusion refers to all people having a sense of educational belonging and involvement in socially meaningful participation (Anderson, 2006; Black, 1996; Frazee, 2003; Hertzman, 2002; Kliwer, 1998; Lord & Hutchison, 2007; Lusthaus & Lusthaus, 1992; Schwartz, 2000). Students with ID are among the population of students with disabilities who attend Ontario secondary schools; however, the majority of students with ID are often excluded from fully participating in the educational system (Bélair et al., 2008; Thousand & Rosenberg, 1997; UNESCO, 2003; Weber & Bennett, 2004). Specifically, a large percentage of secondary students with ID in Ontario are in self-contained classrooms in which they are physically segregated from their peers, and secondary students with ID are provided few, if any, opportunities to interact with their peers who do not have ID (Bélair et al., 2008; UNESCO, 2003; Weber & Bennett, 2004).

Students with ID between 4 and 13 years-of-age are increasingly being included alongside their peers in elementary school and this has been associated with the Ontario Ministry of Education and Training "Education for All" initiative (Bernard et al., 2005; Shaffer, 2005; Thousand & Rosenberg, 1997). When a child with an ID attends elementary school alongside his/her peers without ID, he or she will have had ample opportunities to establish friendships with their peers. Those friendships are essential and developmentally healthy for social and emotional well-being during the transition from elementary to secondary school (Goldstein &

Morgan, 2002; Sciberras, 2002; Shaffer, 2005). Additionally, as students enter secondary school their social networks typically expand. However, students with ID who leave elementary schools, where they have been educated alongside their peers with and without ID, and who transition into a secondary school that is characterized by greater segregation may experience unique social and emotional challenges. Specifically, when students with ID are segregated from the general classroom they may experience a significant decrease in their social networks, which can have a negative impact on their sense of educational belonging, and more generally, their social and emotional development (Anderson, 2006; Frazee, 2003; Hertzman, 2002; Sciberras, 2002; Shaffer, 2005; Weber & Bennett, 2004). In fact, when students who have ID are not included in regular classrooms and when classrooms are comprised of only average achieving students it could be argued that “artificial educational” environments are created (Anderson, 2006, p. 50). Perhaps by providing equal opportunities to participate educationally we can better prepare all students for the diversity that is part of our global communities (Anderson, 2006; Bach, 2002; Baker & Donnelly, 2001; Black, 1996; Frazee, 2003; Frederickson & Cline, 2002; Lord & Hutchinson, 2007; Sapon-Shevin, 2003; Westwood, 2003).

Increasingly, research has demonstrated how educational inclusion is likely to be developmentally healthy for all children (Anderson, 2006; Copeland et al., 2004; Frazee, 2003; Helmstetter, Curry, Brennan, & Sampson-Saul, 1998; McDonnell et al., 2003; Peetsma, Veger, Roeleveld, & Karsten, 2001). A body of literature and research has provided evidence of the social, emotional, and academic gains that are made by all students when students with ID are included at the elementary and secondary school level. However, research that provides students with ID an opportunity to share their transitional experiences and the role of educational inclusion in this process as they enter secondary school has been scarce (Cohen, Forgan, Klinger,

Schumm, & Vaughn, 1998; Copeland et al., 2002; Fisher & Meyer, 2002, Frazee, 2003; McDonnell et al., 2003; Peck, Donaldson, & Pezzoli, 1990). The purpose of this study was to provide students with ID who attended inclusive and segregated elementary schools the opportunity to share how their transitional experiences to secondary school had an impact on them both socially and emotionally, and it explored the role of educational inclusion in this process.

Literature Review

History of Educational Inclusion in Canada

Driven by a “social philosophy of difference”, students with disabilities were in earlier times purposively separated physically and socially from other people and their communities (Tardif-Williams, Trent-Kratz, & Donato, 2009, p. 240; Radford & Park, 1999; Weber & Bennett, 2004; Winzer, 2005). In Canada until the 1970s, students with ID were not educated alongside their peers (Balescut & Eklindh, 2006; Galton, 1869; Radford & Park, 1999; Sobsey, 1994; Stratford, 1991; Weber & Bennett, 2004). Sir Francis Galton’s (1822-1911/1869) methodologies for identifying students’ intelligence quotients (IQ) continue, to some extent, to assist Canadian educators in making educational placement decisions that result in students with ID being placed in self-contained classrooms (Weber & Bennett, 2004). However, this varies from province-to-province, from school board-to-school board and school-to-school.

During the 1960s, feminism, political activism, and the movement toward individual rights were precursors to the “social philosophy of normalization” movement that later followed in the 1970s (Balescut & Eklindh, 2006; Culham & Nind, 2003; Lusthaus & Lusthaus, 1992; Radford & Park, 1999; Tardif-Williams et al., 2009, p. 240; Press; Wolfensberger, 1972/1999). Similarities among all human beings rather than differences were the means for advocating for

the rights of all people with disabilities to be socially included and to have normal human experiences (Weber & Bennett, 2004; Park & French, 1999; Wolfensberger, 1972/1999). Normalization principles provided the impetus for alterations in the way that students with ID were to be educated in Canada (Park & French, 1999). The normalization principle refers to providing opportunities for people with disabilities to experience life as others without disabilities would regularly experience it. Juxtaposed to normalization principles, legislation, and educational practices changed whereby students with ID were increasingly included in the regular classroom alongside their peers without ID (Culham & Nind, 2003; Williamson, McLeskey, Hoppey, & Rentz, 2006). However, it has been argued that normalization fell short of its expectations in the 1970\80s as students with ID, who were placed alongside their peers to learn, were often not given sufficient support in the classroom and afforded fair and equitable educational experiences (Tardif-Williams et al., 2009). It would seem that the voices of students with ID regarding their educational and social needs were not considered in any meaningful way (Bach, 2002).

In Canada, legislation about special educational services was modeled after the legislation implemented in the United States (Weber & Bennett, 2004; Williamson et al., 2006; Yell & Shriner, 1997). In the 1960s, a “dual systems model” in education was adopted and special education services were provided to students with ID separately from the regular educational services (Lusthaus & Lusthaus, 1992, p.100). Changes in the 1980s to the Canadian Charter of Rights and Freedoms (CCRF, 1982) that recognized the rights of persons with disabilities were associated with changes in Ontario provincial education law (e.g., “The Education Amendment Act of 1980, Bill 82 in the province of Ontario”; Weber & Bennett, 2004). For the first time students with disabilities were provided a “continuum of educational

services” that made choices available in special educational services and placements that would provide opportunities for all children to learn alongside their peers (Weber & Bennett, 2004, p.40). However, fragmentation in the way that special educational services were provided to students with disabilities across Canadian provinces continued to be a major barrier for educational inclusion of students with ID (Fryxell & Kennedy, 1995).

For example, the “Education Act” for each Canadian province ensures every child and student with ID will have free and appropriate education but it does not guarantee educational inclusion (Ontario Ministry of Education & Training, 1996/2001; Weber & Bennett, 2004). The degree to which a student is segregated from his/her peers without disabilities is often contingent upon that student’s level of academic functioning and ability to fit into the educational system (Bélair et al., 2008; Weber & Bennett, 2004). Principals, resource teachers, classroom teachers, parents, and the Individual Placement Review Committee determine the extent of a student’s ability to fit into the various educational settings based on the student’s need and best interest. As an example, older students and students with more severe ID are less likely to be placed in regular classroom settings (Bélair et al., 2008; Frazee, 2003; Weber & Bennett, 2004).

Advocacy groups also play a significant role in the educational inclusion of students with ID; however, their level of agreement often differs (Fuchs & Fuchs, 1994; Gartner & Lipsky, 1987; Rueda, Gallego, & Moll, 2000; Stainback & Stainback, 1992; Wang, Reynolds, & Walberg, 1994). Specifically, some advocacy groups lobby to retain the continuum of special education services and placements while others seek to remove the continuum and replace it with full educational inclusion of all students (Bach, 2002; Frazee, 2003; Fuchs & Fuchs, 1994; Kluth, Villa, & Thousand, 2001). Advocacy groups who seek full inclusion often cite the social and emotional benefits for all children being included. Alternatively, advocacy groups who seek a

continuum of services often cite the benefits of a range of settings and supports that meet students' needs and what is in the students' best interest. A continuum of service often provides students with opportunities that range from integration to full inclusion.

Recent "Education for All" initiatives in Ontario have been associated with the educational inclusion of a greater number of students with ID at the elementary level. Despite these advances in educational inclusion, as these students transition into secondary school many of them will continue to face educational segregation from their peers without disabilities (Bernard et al., 2005; Ontario Ministry of Education & Training, 1996/2001; Weber & Bennett, 2004). For the most part, segregation at the secondary school level has often been related to the school's culture of inclusion/exclusion, more challenging academic subjects (math, English, sciences), educators' training for inclusion/accommodations of students with ID, and caregivers' hesitancy concerning inclusion.

Rights, Social Justice, and Educational Access and Inclusion

Legislation and charters provide protection for and support the educational rights of students with disabilities in Canada (Ontario Ministry of Education & Training, 1996; United Nations Convention on the Rights of Children, 1989; United Nations Convention on the Rights of Persons with Disabilities, 2006; United Nations Declaration on the Rights of Disabled Persons, 1975; United Nations Declaration on the Rights of Mentally Retarded Persons, 1971; Weber & Bennett, 2004). They serve as a framework for educational inclusion to safeguard students with ID from experiencing marginalization (Sapon-Shevin, 2003). The Declaration on the Rights of Disabled Persons (DRDP), the United Nations Convention on the Rights of Children (UNCRC, Convention on the Rights of Children, 1989), and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, Convention on the Rights of

Persons with Disabilities, 2006) outline the right of all students to receive an education, regardless of disability. Further, the DRDP clearly identifies access to supports that facilitate the process of educational inclusion of students with disabilities. Clause six states that:

Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counseling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.

Article 28 of the UNCRC outlines the right of all children to have access to a basic education and Article 29 promotes social development and citizenship. Article 24 (Sections 1 & 2) of the UNCRPD (2006) outlines the rights of students with disabilities that specifies the need for educational access and inclusion: “States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels” (Section 1). Additionally, Section 2 specifies that:

In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual's requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion

Having a sense of educational belonging enhances all students' academic, social, and emotional success in secondary school (Bach, 2002; Blanchet, 1999; Department of Justice Canada, 2006; Frazee, 2003; Kluth et al., 2001; Poirier & Goguen, 1986; Sapon-Shevin, 2003; Thomas & Wolfensberger, 1999). Educational access and inclusion needs to be supported by a universal philosophy of inclusion for educational inclusion to be successfully implemented (Lord & Hutchison, 2007; Tardif-Williams et al., 2009; Winzer, 2005). A universal philosophy of inclusion would support the rights of students with ID to have an inclusive educational experience rather than a spectrum of educational services/placements which often creates a barrier for students with ID from accessing their peers (Kluth et al., 2001). The spectrum of educational services refers to the various options that educators can provide to students with ID (Weber & Bennett, 2004) including an educational environment that does not include peers without disabilities.

Interdependence and Educational Inclusion

Inclusion in a broader sense is a philosophy and a practice that values and ensures that the rights and legal entitlement of students are upheld to facilitate a sense of educational belonging (Frazee, 2003). In a practical sense, educational inclusion means placing students with ID into settings or providing them with opportunities where they will have access to their peers without ID.

Developments in the area of social justice have increased access to more inclusive educational environments for students with ID; however, access to inclusive education does not guarantee that students will develop a sense of educational belonging (Allan, 1997/2006; Anderson, 2006; Bach, 2002; Frazee, 2003; Schwartz, 2000; Wiener & Tardif, 2004). The physical space in the regular classroom does not solely represent educational inclusion, and rather physical inclusion must be combined with an educational philosophy that promotes a sense of educational belonging among all students (Anderson, 2006; Baker & Donnelly, 2001; Black, 1996; Frazee, 2003; Fryxell & Kennedy, 1995; Schwartz, 2000). In this way, social justice would best be characterized by the need for interdependence among students rather than simply creating equal opportunities for students (Anderson, 2006). In some educational environments, students with ID are perceived as dependent because of their needs rather than as part of a whole community that benefits from needing each other (Allan, 1997/2006; Lord & Hutchison, 2007; Shevlin & Mona O'Moore, 2000). It can be argued that all students have needs that require some level of support, and from this perspective interdependence among students refers to the mutual support that is achieved through reciprocity in relationships (Shevlin & Mona O'Moore, 2000).

The case of Eaton vs. the Brant County Board of Education, Ontario, Canada (Grover, 2002) highlights this latter point very effectively. Specifically, what was ruled in Emily Eaton's best interest, although well intentioned, formed a physical barrier to accessing her peers without disabilities; whereas, a universal philosophy of inclusion may have ensured that the options for Emily's education included access to her peers without disabilities. This case is one example of how students with ID are often perceived as dependent based on their needs. The Supreme Court of Canada ruled that it would be in Emily Eaton's best interest to be segregated from her peers despite having established previous close relationships with her classmates. At the time, Emily was a 12 year-old female who used a wheelchair, communicated using technological devices, and required visual supports. Emily's special needs circumvented her right to be included alongside her peers because it was considered by the court to be in her best interest (Grover, 2002; Weber & Bennett, 2004). It could be argued that the Board of Education and the Supreme Court of Canada not only circumvented Emily's rights but also her peers' rights to a diverse learning environment that would better prepare them for life in their communities. Additionally, the court's ruling did not highlight that Emily's peers needed her just as much as she needed them.

Academic, Social, and Emotional Impact of Educational Inclusion

Emphasis on academic achievement during secondary school for students to access highly competitive programs in post-secondary institutions and achievement tests in Ontario schools, such as the compulsory "Ontario Secondary School Literacy Test" that must be passed to be eligible to receive a diploma, (Education Quality and Accountability Office, 2007) have created additional barriers for students with ID that impede their access to placements in regular secondary school classrooms. The trend towards competition and

standardized testing that often excludes students with ID originates from government initiatives toward global competitiveness in world economic markets by creating highly educated and skilled populations (Keating & Hertzman, 1999; Organization for Economic Co-operation and Development, 2002). Caregivers of children without ID often cite competition as one of their concerns about the impact that a modified curriculum may have on their children's academic development. On the other hand, caregivers of children with ID report being concerned with the additional frustration their children will have if the curriculum is too advanced (Connor & Ferri, 2007; Garrick Duhaney & Salend, 2000; Palmer et al., 1998; Soodak & Erwin, 2000).

Interestingly, however, Idol (2006) found that state wide American standardized testing scores among students without disabilities were higher for students in secondary schools that practiced highly inclusive pedagogy. The inclusion of peers with disabilities in the regular classroom, in this circumstance, was not academically disadvantageous to other students' learning. Actually, three of the four elementary schools included in this study found improvements in students' scores over 4 years.

For the most part, research has demonstrated how educational inclusion is developmentally healthy for all students (Baker, Wang, & Walberg, 1995; Calberg & Kavale, 1980; Copeland et al., 2004; Cutts & Sigafoos, 2001; Freeman & Alkin, 2000; Helmstetter, et al., 1998; Helmstetter, Peck, & Giangregio, 1994; McDonnell et al., 2003; Nakken & Pijl, 2002; Peetsma, Veger, Roeleveld, & Karsten, 2001; Wang & Baker, 1985-1986). A body of literature and research has provided evidence of the social, emotional, and academic gains that have been associated with educational inclusion of students with ID. (Copeland et al., 2002; Cutts & Sigafoos, 2001; Fisher & Meyer, 2002, Freeman & Alkin, 2000; Helmstetter et al., 1994;

Kennedy, 2002; McDonnell et al., 2003; Mu, Siegel, & Alinder, 2000; Nakken & Pijl, 2002; Shevlin & Mona O'Moore, 2000; Wiener & Tardif, 2004).

Hughes et al.'s (1999, 2000, 2002) research highlights the important social role that students with ID have while interacting with their peers without ID (to date, much of the research has focused on peers without ID as the active agents of educational inclusion; Rillotta & Nettlebeck, 2007; Roeyers, 1996). In the study by Hughes et al. (1999), students aged 15 to 20 years with and without ID were not provided with materials for facilitating collaborative work that would promote social improvements. Instead, the researchers observed the effects of simple physical proximity among students with and without ID for enhancing social improvements. This study failed to yield similar results to studies reviewed in the next paragraph (Hughes et al., 1999). The authors point to the absence of social activities as the reason for their results.

Hughes and her colleagues (2000) provided students ages 16 to 18 years with the opportunity to teach and learn from each other ways of communicating and socially interacting that gave students with ID a more active social role. In this study, researchers developed communication books that were utilized by four males and one female student with ID. The books were comprised of "communication initiators" (p. 157) or opening conversation statements from a collection of 50 topics (e.g., movies, clothes, school events, etc...) that were identified in an earlier study as suitable for a diverse group of adolescent students (Hughes, Harmer, Killian, & Niarhos, 1995). The books were used for initiating social interactions that in previous research was a social role reserved only for those without ID. Social gains were found among the five students with ID and they reported substantially positive experiences with making friends using their communication books during their social interactions. Additionally, students without ID who volunteered as conversational partners reported having "appropriate and

enjoyable conversations with the five students with ID”, after the students with ID were trained to use their communication books (p. 164). Hughes and her colleagues (2000) provide compelling evidence in this study that successful educational inclusion is associated with students’ interdependence; all students were required to work collaboratively, as part of a larger whole, to learn how to use their communication books. As well, researchers’ expectations for social improvements among all students were exceeded because social improvements continued to be maintained after the intervention had ceased.

Similar to the research conducted by Hughes et al. (2000, 2002), Frazee’s (2003) work has provided a rare but compelling glimpse into the educational inclusion experiences of students aged 15 to 18 years with and without ID. Frazee’s participants took part in a series of email dialogues based on thematic discourses that explicitly demonstrated the social and emotional benefits of educational inclusion for all students. Many students reported a general sense of well-being and educational belonging that they experienced from being included with their peers with and without ID. Additionally, Frazee’s participants highlighted that educational inclusion was important to their educational sense of belonging and that any other alternative may compromise all students’ rights to belong.

In one meta-analysis it was shown that educational inclusion yielded positive social, emotional, and academic outcomes for all students (Hunt & Goetz, 1997). Hunt and Goetz (1997) examined 19 studies that consistently reported positive social and emotional gains among students with and without ID in elementary schools when students with ID were included in the regular classroom. Freeman and Alkin (2000) examined 25 studies about social outcomes and 11 studies about academic outcomes of students with ID in elementary and high school and the role of educational inclusion in those studies. In examining both quantitative and qualitative studies,

Freeman and Alkin found evidence that educational inclusion was associated with students' feelings of social acceptance and sense of educational belonging within their schools. In this regard, the authors noted that social competence appeared to be the largest contributing factor for students' feelings of acceptance and educational belonging. In yet another meta-analysis of 11 empirical studies, Wang and Baker (1985-1986) found significant advantages in achievement and self-worth among kindergarten to grade six elementary students with ID who were placed in more inclusive educational settings, as compared to students with ID who were placed in self-contained locations. Further, Rillotta and Nettlebeck (2007) had successful social outcomes among students without disabilities when educational inclusion was paired with awareness programs that touted the association between interdependence among students and social gains.

Like students without ID, those with ID experience poor social and emotional outcomes when they were socially excluded (Allan, 1997, 2006; Chesley & Calaluce, 1997; Fisher & Meyer, 2002; Frazee, 2003; Sunwolf & Leets, 2004). Peer rejection, isolation, loneliness, social anxiety, inappropriate or negative social behaviours, and depression have often been cited as outcomes associated with exclusion of students with and without ID (Allan, 1997, 2006; Asher, Parkhurst, Hymel, & Williams, 1990; Borthwick-Duffy, Lane, & Widaman, 1997; Chesley & Calaluce, 1997; Fisher & Meyer, 2002; Frazee, 2003; Heiman, 2001; Heiman & Margalit, 1999; Qualter, 2003; Sunwolf & Leets, 2004). In a study conducted by Fisher and Meyer (2002), participants with ID aged 6 to 19 years who were excluded from interacting with their peers without ID had poor social developmental outcomes when compared to their same aged peers who had been included in the regular classroom. Further, Fisher (1999) reported on the educational inclusion experiences of students without ID by conducting twelve focus groups in a secondary school that practiced educational inclusion. The 257 students in grade 9 to 12

interviewed supported educational inclusion of students with ID, as they felt that it contributed significantly to positive social outcomes for all students. For example, a student was cited as expressing how much he had learned about the impact of his good and bad social behaviours on his peers with ID. Specifically, they focused on the positive social outcomes that students experienced from diversity in the classroom. Similarly, students with ID were perceived by peers without ID to be part of their schools in a way that would prepare all students for their futures (Rillotta & Nettlebeck, 2007; Roeyers, 1996). Moreover, Heiman and Margalit (1998) examined the relationship between educational placement and emotional well-being among students aged 11 to 16 years with ID, and found that students who were in self-contained classrooms (in schools that had regular classrooms) reported higher rates of loneliness and depression (Heiman, 2001). Finally, in a meta-analysis conducted by Carlberg and Kavale (1980) including 50 studies that focused on achievement, behaviour and social outcomes, it was found that students, 6 to 14 years of age, with ID were most disadvantaged when placed in special versus regular classrooms.

Given the positive developmental benefits of educational inclusion for students with ID, it is surprising that only a few researchers (e.g., Curran Neild, Stoner-Eby, & Furstenberg, 2008; Noland et al., 2007) have focused on the social and emotional impact of the transition process from elementary to secondary school among this group of students. Although in the work conducted by Noland et al. (2007) attention is focused on transitioning, these researchers examined techniques for successful transitioning of students with Autism into secondary school and neglected to discuss the process and social or emotional impact of elementary-secondary transitions among students with various types of ID. Instead, much of the research focused on various types of students' with ID aged 15 to 20 years and their inclusion experiences while in secondary school. Particular emphasis in much of the research has been about social competence

associated with inclusion. As discussed earlier, many students with and without disabilities may encounter difficulties in adjusting to secondary school. However, students with ID may experience greater adjustment difficulties because transitioning to secondary school often represents a unique situation when educational access and inclusion become restricted for the first time. Clearly, there is a need for research that focuses on the unique transitioning experiences of students with ID.

Caregivers and Educational Inclusion

The perspectives of caregivers regarding the educational inclusion of their children with ID plays a large role in determining whether they will advocate for their children to transition into secondary schools alongside their peers in regular classrooms (Garrick Duhaney & Salend, 2000; Leyser & Kirk, 2004; Palmer, Borthwick-Duffy, & Widaman, 1998; Palmer, Fuller, Arora, & Nelson, 2001; Soodak & Erwin, 2000). Caregivers who consider social skills development as paramount for their students with and without ID are reported as having a more positive perspective of educational inclusion of children with ID (Garrick Duhaney & Salend, 2000; Leyser & Kirk, 2004; Palmer et al., 1998; Palmer et al., 2001; Soodak & Erwin, 2000). Caregivers who value social skills development recognize that social interdependence between students with and without ID can facilitate healthy social and emotional outcomes because learning takes place in diverse environments. However, factors that often inhibit the positive perspectives of caregivers about educational inclusion include the fear that children with ID will be rejected by their peers without ID, the potential lack of access to specialized services and qualified personnel in a regular classroom, the lack of administrative and teacher training, and the potential that caregivers may have to commit more time to their children's education

(Chesley & Calaluce, 1997; Connor & Ferri, 2007; Garrick Duhaney & Salend, 2000; Hilton & Liberty, 1992; Leyser & Kirk, 2004; Rainforth, 2000; Wasburn-Moses, 2006; White, 2002).

It would appear that multiple factors determine the perspectives of caregivers about educational inclusion and their decision to advocate with secondary school administrators and teachers to provide their children with the opportunities to be placed in a regular classroom. To shed light on the educational experiences of students with ID, it might be particularly helpful to understand how their caregivers perceive the transition from elementary to secondary school and the role of educational inclusion in this process. For instance, caregivers may have substantial influence on the ways that students with ID understand, interpret and experience what it means to be included. Clearly there is a need for research that attempts to uncover the complexity underlying how caregivers perceive, and students with ID understand, interpret and experience, the transition from elementary to secondary school and the role of educational inclusion in this process.

A Model for Understanding the Transitional Experiences of Students to Secondary School & the Role of Educational Inclusion

Scholars and researchers consider students' transitional experiences from elementary to secondary school to be a "critical life event" (Sirsch, 2003, p. 385), one that is experienced by all adolescents (Curran Neild et al., 2008; Gillison et al., 2008; Jindal-Snape & Foggie, 2008; Newman et al., 2007; Rudolph et al., 2001; Seidman, Allen, Aber, Mitchell, & Feinman, 1994; Sirsch, 2003; Smith et al., 2008). The transition from elementary to secondary school is accompanied by physical changes in the size of schools and classrooms (e.g., most often these are both larger), different rules and regulations, more teachers, larger peer groups, and more academic pressures (Sirsch, 2003). Students' individual reactions to these social and academic

changes must be considered (Gillison et al., 2008; Sirsch, 2003). While research findings document mostly positive social, emotional, and academic outcomes in relation to students' transitional experiences from elementary to secondary school (Gillison, 2008; Seidman et al., 1994; Sirsch, 2003), there also appears to be a small percentage of students who experience negative social, emotional, and academic outcomes during this important developmental period (Curran Neild et al., 2008; Jindal-Snape & Foggie, 2008; Newman et al., 2007; Rudolph et al., 2001). In particular, some at-risk students (e.g., experiencing socioeconomic disadvantage, learning disabilities, behavioural challenges, or ethnic/racial minority status or prejudice) appear to face unique challenges in transitioning from elementary to secondary school (Curran Neild et al., 2008). Social support networks, caregiver support, a sense of educational belonging, and perceiving the transition to secondary school as a healthy challenge rather than a negative threat were strong predictors that students would successfully transition into secondary school (Curran Neild et al., 2008; Gillison et al., 2008; Jindal-Snape & Foggie, 2008; Newman et al., 2007; Rudolph et al., 2001; Seidman et al., 1994; Sirsch, 2003; Smith et al., 2008). Interestingly, little research has focused on how these latter predictors are associated with the quality of transitional experiences among students with ID (Cohen et al., 1998; Copeland et al., 2002; Curran Neild et al., 2008; Fisher & Meyer, 2002; Frazee, 2003; McDonnell et al., 2003; Peck et al., 1990). Clearly, research is needed that examines the unique social and emotional challenges that students with ID may face as they transition from inclusive elementary to segregated secondary settings.

Figure 1.1 provides a model for understanding the various pathways that might elucidate the transitional experiences of students with and without ID from elementary to secondary

school. This model highlights both areas of commonality and diversity in the educational transitional experiences of students with and without ID.

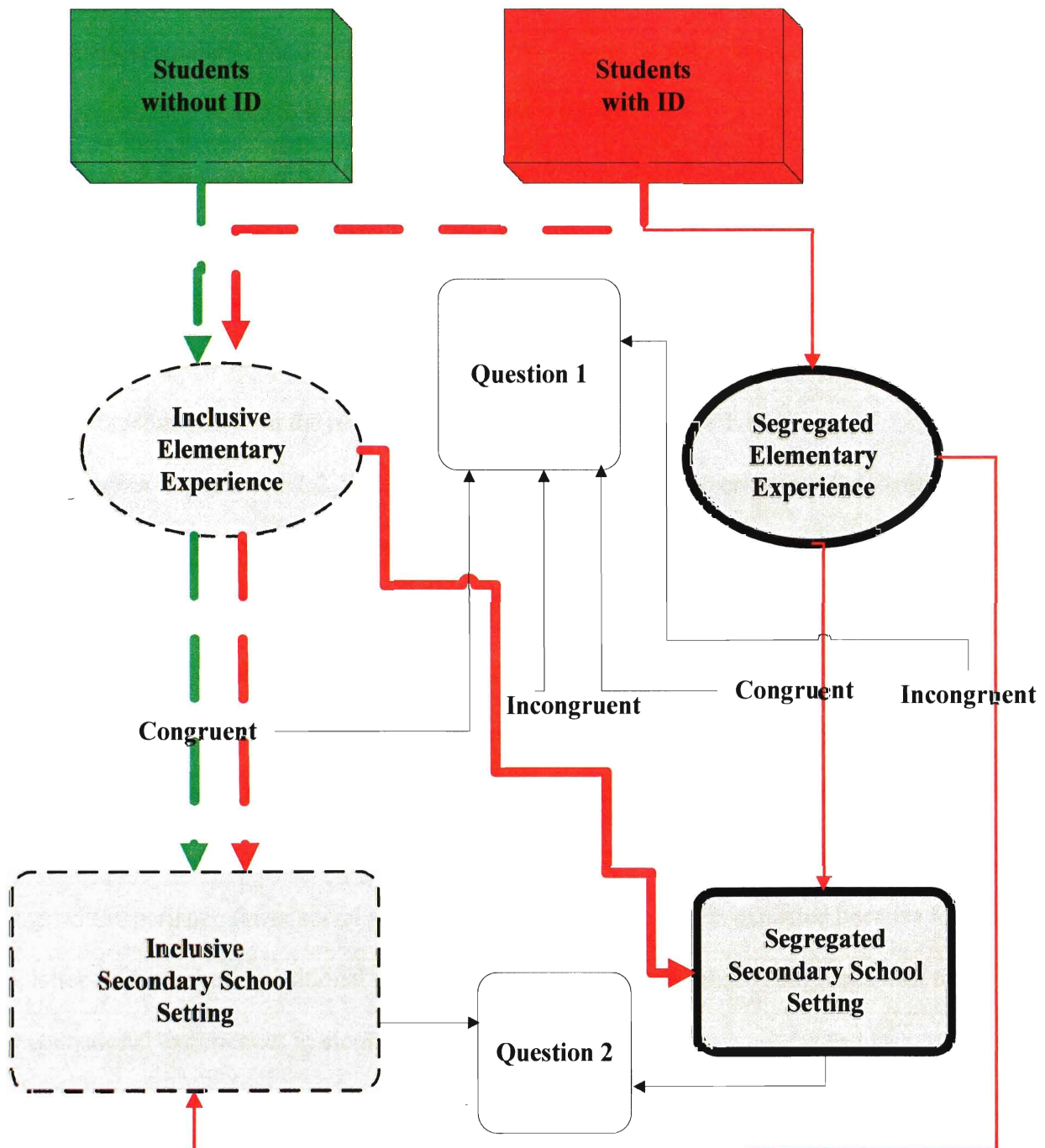
At the top of figure 1.1, both students with and without ID are indicated using different coloured boxes to distinguish possible differences in the transitional pathways of these two groups of students. The transitional pathways of students with and without ID who had inclusive elementary school experiences are delineated by a similarly thick line, thus highlighting this as a shared experience. In contrast, the transitional pathways of students with ID who experienced segregated, versus inclusive, elementary school experiences are delineated by a thinner line. An inclusive elementary and secondary experience is highlighted using a circle and rectangle defined by broken lines, thus representing open and flexible educational settings. On the other hand, a segregated elementary and secondary school experience is highlighted using a circle and a rectangle defined by a solid thick line, thus emphasizing the closed and self-contained nature of these educational settings. On the left side of figure 1.1 the transitional experiences of students with and without ID are noted as being congruent with their elementary school experiences; both educational experiences are defined by inclusionary practices. Although these students will experience a period of adjustment to secondary school, for the most part, it is argued that their transitional experiences will be characterized by fewer challenges and will be more successful (Curran Neild et al., 2008).

The middle of figure 1.1 highlights the transitional pathways of students with ID who first experienced inclusive elementary schools and then entered into segregated secondary schools – the target group of students whose educational experiences will be carefully explored in this study. The pathway is illustrated with a dark, solid, jagged line to represent the incongruity in these students' educational experiences, while noting their experience as different

from their peers with and without ID who transitioned into inclusive secondary settings. In this case, students with ID who were educated alongside their peers in elementary school and then transitioned into segregated secondary settings may experience unique social and emotional challenges, as compared with their peers who experienced inclusive or segregated elementary-secondary school transitions.

Curran Neild et al. (2008) examined urban elementary-secondary school transitions among various types of students aged 13 to 15 years in Philadelphia. These researchers found that transitioning from segregated elementary to segregated secondary school settings did not impact the social or emotional development of students. Specifically, there did not appear to be any adjustment difficulties among students who continued to be educated in segregated settings. Note, however, that Curran Neild et al.'s study did not examine the transitional experiences of at-risk or vulnerable students with ID. This transition is especially important to examine among students with ID because serious social, emotional, and academic challenges may arise when these students encounter educational environments that stand in stark contrast to those from which they graduated (i.e., inclusive elementary to segregated secondary school settings). On this note, figure 1.1 highlights on the right the transitional experiences of students with ID who had segregated elementary experiences using a much thinner line, to clearly demarcate this group from their peers with ID who had inclusive elementary experiences. Based on the research previously discussed, it is expected that students with ID who experience segregated elementary to inclusive secondary school transitions are likely to benefit socially and emotionally but there may be a period of challenging adjustments because it is incongruent with their elementary experiences.

Figure 1.1: A Model Highlighting Transitional Experiences and Possible Pathways from Elementary to Secondary Schools between Students with and without ID



Research Questions and Expectations

Research Questions and Expectations

Research Question 1. In what way are students with ID socially and emotionally affected by elementary/secondary school transitions that are incongruous in nature (i.e., going from an inclusive elementary school to a segregated secondary school)?

Research Expectation 1.1. It is expected that the transitional experiences of students with ID who experienced educational inclusion in elementary school and who transitioned to segregated secondary settings will be characterized by greater negative social and emotional challenges because it is incongruent with their inclusive elementary experiences and thought to be disadvantageous based on the research reviewed earlier (see figure 1.1).

Research Expectation 1.2. It is expected that the transition experiences of students with ID who experienced educational segregation in elementary school and who transitioned to inclusive secondary settings will be characterized by greater positive social and emotional outcomes because it is incongruent with their segregated elementary experiences and thought to be advantageous based on the research reviewed earlier (see figure 1.1).

Research Expectation 1.3. It is expected that students with ID who experienced educational segregation in elementary school and who transitioned to segregated secondary settings will experience fewer social and emotional difficulties. This is expected because for these latter students their transitional experiences to secondary school are congruent with their prior educational experiences in elementary school (see figure 1.1).

Research Expectation 1.4. It is expected that students with ID who experienced educational inclusion in elementary school and who transitioned to inclusive secondary settings will report experiencing some degree of social and emotional adjustment but will for the most

part report experiencing positive social and emotional outcomes because it is congruent with their inclusive elementary experiences and thought to be advantageous based on the research reviewed earlier (see figure 1.1).

Research Question 2. What role does educational inclusion play during the secondary school transition experiences' of students with ID?

Research Expectation 2. It is expected that educational inclusion will play a critical role during the transition to secondary school among students with ID, with students' and caregivers' reporting more positive social and emotional outcomes when experiencing more inclusive educational settings (see figure 1.1).

Rationale for Research Questions 1 & 2. As described earlier in this study, minimal research has examined the critical time period when students with ID transition into secondary schools and how that transition and the extent to which they were included in secondary schools affects their social and emotional development (Cohen et al., 1998; Copeland et al., 2002; Fisher & Meyer, 2002; Frazee, 2003; McDonnell et al., 2003; Peck et al., 1990). Transitional experiences refer to a time period when adolescents leave elementary schools typically at the age of 13 or 14 years to attend secondary schools. It is essential to learn more about how students with ID experience this latter transition (Gillison et al., 2008; Newman et al., 2007; Siedman et al., 1994; Sirsch, 2003; Smith et al., 2008). Positive transitions would be associated with students with ID having fewer social and emotional challenges in adapting to their new schools; whereas, negative transitions would be associated with students' reports of experiencing greater social and emotional challenges in adapting to their new schools.

To fully understand the impact of elementary/secondary school transitional experiences among students with ID, it is essential to also consider the role of educational inclusion in this

process. Specifically, as outlined in figure 1.1, the degree to which students with ID experience inclusive settings in elementary school might be associated with unique social and emotional challenges when they transition to segregated secondary school settings. Comparing the educational inclusion experiences of students with ID in elementary to secondary school will help to clarify whether these differences are related to differential reports of positive or negative transitional experiences. The educational inclusion experiences of students with ID are characterized by opportunities to interact socially with and learn alongside their peers with and without ID.

As discussed in the previous section, research has provided compelling evidence that educational inclusion is socially and emotionally beneficial for students with ID (Cohen et al., 1998; Copeland et al., 2002; Fisher & Meyer, 2002; Frazee, 2003; McDonnell et al., 2003; Peck et al., 1990). The social skills development and emotional maturation that occurs during secondary school are essential for preparing students with ID in making successful transitions into their communities or postsecondary opportunities (Sabbatino & Macrine, 2007). Peer rejection, isolation, loneliness, social anxiety, inappropriate or negative social behaviours, and depression have often been cited as the outcomes associated with exclusion of students with and without ID (Allan, 1997/2006; Asher et al., 1990; Borthwick-Duffy et al., 1997; Chesley & Calaluce, 1997; Fisher & Meyer, 2002; Frazee, 2003; Heiman, 2001; Qualter, 2003; Sunwolf & Leets, 2004). Social and emotional challenges may inhibit students with ID from learning, making friends, and acquiring essential social skills for successfully transitioning into and out of secondary school. The social and emotional challenges experienced in secondary school may continue to impede students with ID as they transition into their communities and postsecondary institutions/activities creating barriers for future successes (Griffiths, Stavrakaki, & Summers,

2002). Having a sense of educational belonging may be essential for students to successfully transition into secondary school (Gillison et al., 2008; Newman et al., 2007; Rudolph et al., 2001; Sabbatino & Macrine, 2007; Siedman et al., 1994; Sirsch, 2003; Smith et al., 2008).

Chapter 2

Methods

Participants

Students with ID. The covering and invitation letters (see Appendices A and B) were sent to a total of 115 families and the first 6 families that agreed to participate and met the inclusion criteria were included. Note that one of the 6 families wanted to share the unique experiences of both of their two children; however, one of their two children chose to not assent to participate at the time of his interview. Of the six students with ID who wanted to participate five were able to meet the informed assent criteria to participate and were assigned codes to identify them that were sequenced according to the order in which they volunteered to participate. Although it would have been ideal to include every student with ID in this study, such an approach may have limited the conclusions that were drawn from the results because some students with ID would have been unable to provide responses. In one case, this was the circumstance with one participant who was unable to demonstrate his understanding of assent through language. However, attempts were made to use his picture exchange card system to determine his level of understanding but assent could not be reliably and meaningfully obtained. Finally, to provide meaningful comparisons, it was necessary that students with ID who were included in this study have attended elementary schools where they were included in or segregated from the regular classroom. Subsequently the five participants who did assent to participate in this research study will be referred to as C1, C2b, C3, C4 and C5 to ensure their confidentiality and anonymity. The one caregiver (P6), as noted above, who provided information about her son's experiences in elementary to secondary school consented to have her reports of her son's experiences shared,

even though he himself did not meet the informed assent criteria. Subsequently her account of her son's experiences will be referred to as P6.

The following disabilities were reported for the six participants: 3 with Down Syndrome; 1 with William Syndrome; 2 Autism Spectrum Disorder. The children with ID who were included in this study had already entered secondary school because this study focused on their transitional experiences to secondary schools. One student was in grade 10, two students were in grade 11, three were in grade 12 but one had already graduated in 2006 but returned to continue attending school until she reached the age of 21. According to legislation a student is entitled to attend secondary school until they are aged 21 years (Education Act, 1996). To be included in this study, students with ID had to match the following criteria:

- Must be between the ages of 13 to 22 years;
- Have an intellectual disability;
- Be able to communicate verbally;
- Transitioned from grade 8 to grade 9 in the past 9 years;
- Attended elementary school where they were included or segregated from the regular classroom; and
- Living in a family environment and not a group home.

Rationale for inclusion criteria. The inclusion criteria were necessary to ensure that participants were able to engage in and contribute meaningfully to the study. The age range was 17 to 21 years with the average age of participants being 18 years; all the adolescents were still attending secondary school. Although some students' ages would classify them as youth rather than adolescents; however, these students' prolonged secondary school experiences extends their experience of being an adolescent. The group was comprised of three females and three males.

Information regarding students' intellectual quotients (IQ) was not collected; however, their affiliation with Community Living's Family Support Services was an indicator that they had been identified formally as having an ID – a necessary inclusion criterion for participation in this study. It was also imperative that participants who were selected were able to participate through some form of verbal communication. In this study, none of the participants needed to use assisted communication devices (e.g., computer) to communicate.

Operational Definitions. In this study, educational inclusion in elementary and secondary school referred to cases where students with ID were placed in a regular classroom to be educated alongside peers with or without ID for approximately 80 percent or more of the day with minimal segregation from their peers. A segregated elementary or secondary school referred to cases when students with ID were placed in a self-contained classroom to be educated without peers who do not have an ID for approximately 80 percent or more of the day. Calculation of the extent to which a student with ID is included in the regular class room, needs to include consideration of additional supports or services that are better provided outside of the regular classroom. Often additional supports or services (e.g., speech services, occupational therapy, physiotherapy, etc.) are provided to students with ID outside of the regular classroom; but for only a small proportion of the day. These types of supports or services are often provided in another location, such as a resource room, where the equipment/tools to provide the support or service is available and will not interrupt other students' learning in the regular classroom. Weber and Bennet (2004) reported on the various types of special education placements and on average 18% of elementary and secondary students were reported receiving supports or services outside of the regular classroom (p. 40). The criteria of 80% in or outside of the regular classroom provides consideration for a continuum of services or supports that may be required

by students with ID outside of the regular classroom but it also sets a limit whereby the larger percentage of a students' with ID day is spent with their peers with and without disabilities.

Classification of students' transition experiences. Classifying students' transitional experiences from elementary to secondary school as congruent or incongruent was based on caregivers' reports of their children's school histories. Caregivers were asked to indicate the type of classroom placement their children had experienced in both elementary and secondary (grade 9) school. Specifically, caregivers were asked if their children experienced segregated or regular classrooms in both elementary and secondary school. In one circumstance, a caregiver reported that her child was included up to grade 5 and then segregated for grade 6. Based on this child's experiences of being segregated, his caregiver decided to fast track him to high school instead of attending grade 8. This students' transitional experience could not be easily classified; therefore, he was classified as having a congruent/incongruent transitional experience (see figure 1.2) which will be discussed in further detail in the findings section. Caregivers were also asked to identify how many hours of services, if any, their children received outside of the regular classroom if they were included in elementary or secondary school. As well, caregivers were asked to report in how many classes, if any, their children were included with the regular classroom (e.g., one caregiver reported that her son attended art and physical education classes with students with and without ID in secondary school; however, the majority of his day was spent in a segregated classroom where the teacher to student ratio was higher to meet his specific learning needs). Ascertaining the number of hours of service children received outside of the regular classroom or the extent to which they were included in the regular classroom in elementary and secondary school assisted with determining whether students with ID were spending equal to or less or more than 80% of their day away from their peers with and without

ID. Table 1 shows the classifications of the six students in this study as 4 congruent, 1 incongruent and 1 congruent/incongruent.

Table 1

Classification of students' transitional experiences

	Congruent	Incongruent	Congruent/Incongruent
Number of Students	4	1	1

Among the 5 students with ID who assented to participate in this study two caregivers reported that their children were segregated in both elementary and secondary school; therefore, these students were classified as having **congruent and segregated** ($n = 2$) transitional experiences (see figure 1.2). Three caregivers reported that their children were included in the regular classroom up to grade 8. Of the three, two caregivers reported that their children continued to be included in the regular classroom in grade 9; therefore, these students were classified as having a **congruent and included** ($n = 2$) transitional experience (see figure 1.2). These students' caregivers reported that they only had one period, referred to as "learning strategies", where they were not in the regular classroom. The other student who had an inclusive elementary experience was classified as having an **incongruent and segregated** ($n = 1$) experience because his caregiver reported that he was segregated from the regular classroom for more than 80% of the day in secondary school. Lastly, the one caregiver who had agreed to participate, but whose son did not meet the assent criteria, reported her child was included up to grade 6 and then was segregated for grade 7. The caregiver decided to fast track her son to grade 9 based on unfavourable social and emotional outcomes (aggressive behaviour, developmental

regression (drooling), emotional outbursts (crying)) that were reported by the caregiver to be associated with his segregation in his elementary experience. Classifying this student was challenging as the majority of his elementary experience was inclusive and his grade 6/7 year was sporadic due to his reported reaction to being segregated. This student's classification was determined to be both ***incongruent and congruent*** ($n = 1$) (see figure 1.2). First, it was determined to be incongruent because his inclusive elementary experience was longer than his segregated elementary experience and when he transitioned to grade 9 he was slowly transitioned (gradual attendance that increased over time over 4 months in grade 9) and placed into a segregated classroom. Second, this student's classification was also determined to be congruent because technically he went from a segregated to a segregated classroom as he left elementary school and entered secondary school. However, some inclusion in the regular classroom was integrated towards the end of this student's grade 9 year that was congruent with his inclusive elementary experiences but his inclusion was less than 80% in the regular classroom. Recall that the purpose of this study was to explore the role of educational inclusion during the transitional experiences of students with ID as they moved from elementary to secondary school. Therefore, comparisons were made between those students with ID who transitioned from segregated elementary to inclusive/segregated secondary settings to highlight the unique social and emotional challenges that students with ID experienced when they left inclusive elementary and entered segregated secondary settings.

A concerted effort was undertaken to try to balance the number of participants who experienced inclusive to segregated, segregated to inclusive, segregated to segregated versus inclusive to inclusive secondary school transitions. Specifically, a goal of this study was to recruit three participants from each of the four transitional pathways (see figure 1.1.) to make

comparisons between these students' experiences. However, due to the difficulty associated with recruiting participants with ID and their family members and a low response rate in this study, comparisons of students could only be made for students who had transitioned from elementary to secondary school settings that were: congruent - inclusive to inclusive and segregated to segregated (see figure 1.2); and incongruent – inclusive to segregated (see figure 1.2).

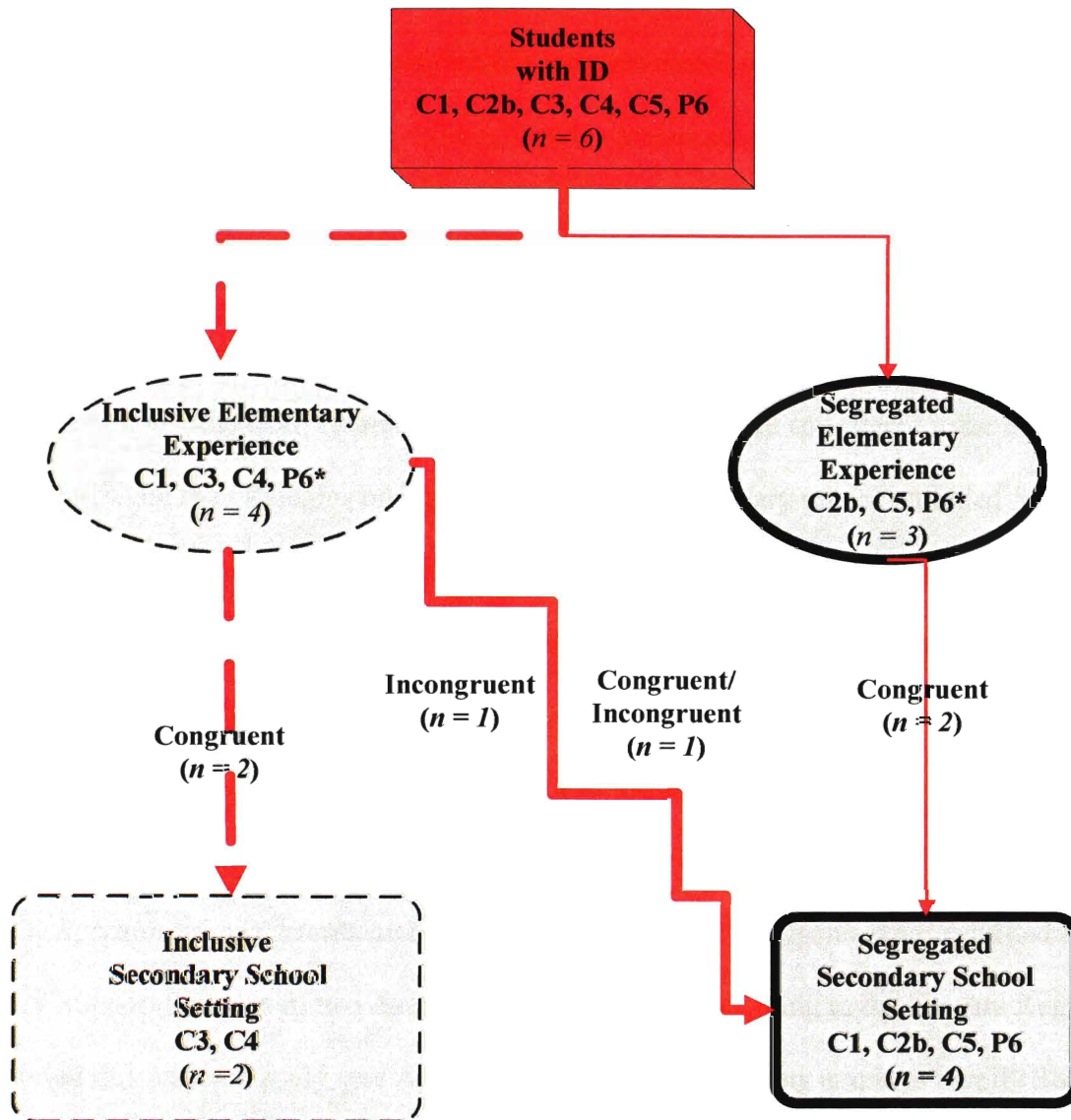
Comparisons were not possible between students who had transitioned from elementary to secondary settings that were incongruent – segregated to inclusive. Therefore, students who followed the transitional pathway from segregated elementary experience to inclusive secondary school setting were not included in this study. This latter finding is consistent with the body of research reviewed earlier in this study. Specifically, those in segregated elementary environments were typically reported in the research as having more severe disabilities that were considered to be better supported in segregated secondary school settings (Bélair et al., 2008; Frazee, 2003; Weber & Bennett, 2004). Table 2 and figure 1.2 show the categories which were comparable between students' with ID congruent and incongruent transitional experiences.

Table 2

Comparable categories of students' transitional experiences

Transitional Experiences	Congruent	Incongruent	Congruent/ Incongruent
Inclusion-Inclusion	2		
Segregated-Segregated	2		
Inclusion-Segregated		1	
Inclusion/Segregated-Segregated			1
Totals	4	1	1

Figure 1.2: A Model Highlighting Transitional Experiences and Pathways from Elementary to Secondary Schools between Students with ID Included in this Study



*Note P6 is represented in both elementary educational experiences as he was included up to grade 6 and his attendance during his 6/7th year was reported to be sporadic in a segregated environment as he transitioned into a segregated secondary school setting.

Caregivers. The first six of eight caregivers to contact the researcher who agreed to participate were included in this study after 115 families with children who have ID were sent covering and invitation letters (see Appendices A and B) to participate in this study. The six caregivers who consented to participate were assigned a code to identify them and these were sequenced and matched with their children's code number according to the order in which they volunteered to participate. Subsequently the six caregivers throughout this study will be referred to as P1, P2, P3, P4, P5, and P6 to ensure their confidentiality and anonymity. It was thought that caregivers who were most involved with their children's schools and who were living with them during their transition from elementary to secondary school were considered to be in the best position to share their thoughts on how the transition to secondary school unfolded for their children. However, in some cases, both caregivers wanted to participate in the study and they were provided the opportunity to stay during the interviews with the caregivers identified as having been most involved with their children's schools (thus the data for interviews P2 and P3 were further coded as P2a, P2b, P3a and P3b). The females were 'a' and males were 'b'. In this study, caregivers were all biologically related to their children.

Recruitment procedures and ethical considerations. Participants were recruited from Family Support Services in two Associations for Community Living in the Niagara Region that supported this research study (see Appendix C). Community Living employs Family Support Workers (FSW) who have been assigned a caseload of families with children who have ID. FSW, in some circumstances, have known their families since the birth of the child with an ID. Clearly, FSW were considered to be in the most ideal position to identify potential participants because they maintained close relationships with and had extensive knowledge about the families they support. In a sense, FSW were gatekeepers who assisted the researcher in identifying

potential participants from their caseloads who they knew matched the inclusion criteria for this research study, but they were not made aware of the specific families that were included in this research study. To address selection bias, it was decided that participants who volunteered first to be contacted were to be selected in random order of having volunteered. However, due to the low response rate all participants who contacted the researcher and who met the criteria for the study and informed assent were included in this study. Inherent to the group that did participate appeared to be their willingness to volunteer to participate. Further, it is possible that the children among the group that did participate in this study experienced more positive transitional experiences; whereas, families with children who may have had negative transitional experiences might have been underrepresented in this study.

All caregivers and their children with ID who matched the selection criteria in both agencies were invited to take part in the research study through covering letters and invitation letters (see Appendices A and B) that were mailed by the FSW on behalf of the researcher. The covering letters (see Appendix A) were used as the researcher was a member of the board of directors and was granted leave from the board while her research was to be implemented. It was identified by the researcher that some families may have known her as a result of her years of service as a board member and as a member of her community in the Niagara region. To avoid the potential that some families who knew the researcher might have felt obligated out of familiarity with the researcher to participate, the covering letter from the agency provided an additional measure for ensuring participants were not inadvertently coerced. The relationship between FSW and their families was confidential and FSW made the initial contact with potential participants that served to maintain participants' confidentiality. However, the invitation letter was clearly different from the Family Support Services' usual correspondence as

the invitation letters were sent on Brock University letter head (see Appendix B) to ensure that families did not misinterpret the research study as being a service provided by their FSW. As well, the invitation letter clearly outlined that families' decisions to participate would in no way affect their relationship with their FSW or the services that they received from the agency. FSW had no investment or interest in the research study to coerce participation, but having them as the initial contact avoided potentially disruptive or intrusive letters or phone calls from the researcher that might have been perceived as research study solicitation. Two weeks after covering letters and invitation letters were mailed to families, FSW conducted follow-up phone calls using a script provided to them by the Principal Researcher (see Appendix D) to contact families that had received invitation letters to remind them of the opportunity to participate in the researcher's study. The rationale for having FSW conduct follow-up phone calls was to maintain families' confidentiality. FSW had no investment or interest in the research study to coerce participation; however, having them serve as the follow-up contact helped to avoid any potentially disruptive or intrusive letters or phone calls from the researcher that might have been perceived as research study solicitation. As well, it provided potential participants who may have not had the opportunity to review the covering and invitation letters sent on behalf of the researcher by the FSW a second chance for being included in the opportunity to participate in the research study.

Caregivers were instructed in the covering and invitation letters (see Appendices A and B) to contact the researcher directly at a confidential phone number if they were interested in participating with or without their children. Caregivers were asked to leave their names and phone numbers via a voicemail system to which only the researcher had the password and access. Potential participants' names and phone numbers were recorded on the Appointment

Form (see Appendix E). All contact information was deleted from the voicemail after the first contact with participants was established. Appointments were recorded on a form (see Appendix E) that included caregivers' names, students' names, addresses, dates and times of appointments, phone numbers and code identifiers. The researcher phoned potential participants back using the phone script (see Appendix F) to set up appointments where the nature of the study was explained to caregivers. If caregivers expressed an interest in participating after they had received more information about the study, then caregivers and their children's interviews were conducted at that time. However, before any interviews began informed consent from the caregivers and assent from the students with ID were obtained (see Appendices G and H). Participants who booked appointments to find out more about the research study had a 1 in 7 chance of winning an Apple Ipod Nano (see Appendix I). It was 1 in 7 because out of the six families who booked appointments with the researcher one family had two children that expressed an interest in participating in this study and the draw was not contingent upon whether children assented to participate. All appointments with the caregivers and their children commenced with a review of the invitation letter, followed by a review of the caregivers' informed consent and the children's assent activity, and ended with opportunities for the caregivers and their children to ask questions about the research study.

The process of obtaining informed assent from students with ID. With any research there are potential harms that may result from a participant volunteering to be part of the research. In this study, participants with ID represented a population of students who had inherent vulnerabilities. Particular caution was taken in obtaining informed assent from these students. An additional activity was used to obtain informed assent (see Appendix H) from the children using Snelgrove's (2006) pedagogical approach for informing children with ID about research and

their rights. Further information and discussion concerning this process can be referred to in Appendix L.

Additional reasons for excluding participants' data. In addition to ensuring that informed consent and assent were obtained, participants who exhibited any behaviours (e.g., avoid eye contact, increase in repetitive activities, leaves seat) or anxiety as a result of their participation in the research were immediately thanked for their participation, debriefed on their participation, and helped to fill out a ballot for the draw. Further, any disclosure of abuse, neglect, and threat or harm from others, to self or toward others or summons from a subpoena to testify required a breach in confidentiality and had to be reported and caregivers were to be informed of the need to breach confidentiality in advance of their participation in this study. No incidences of breach of confidentiality occurred in this study. Moreover, if it was suspected that students with ID were participating because they were coerced by their caregivers they would have been thanked for their participation and provided a draw ballot. No incidences of suspected coercion were observed in this study. However, the caregiver of the child who did not meet the criteria for assent to be interviewed provided informed consent for the researcher to use her account of her son's experiences while transitioning from elementary to secondary school.

Research assistants (RAs) were recruited to assist in the data collection and analysis phase of the study. The RAs were former or current graduate students and underwent training for collecting the data in partnership with the researcher (R). As well, both RAs assisted with transcribing the digitally recorded interviews. Using the RAs who assisted with interviewing to transcribe the data was most effective in capturing information that may have been hard to detect on the digital recorder due to participants' low voice volume, body language, inaudible gestures, or speech impairments. Both of the RAs signed confidentiality agreements (see Appendix J).

Design and Procedures

Design. The design of this study included the collection of data from multiple sources. The qualitative approach adopted in this study provided rich in-depth information that provided opportunities for exploring the commonalities and differences in the transitional experiences of students with ID and the role of educational inclusion in that process, while building on past research. Additionally, qualitative methodologies have been recognized by researchers as the most effective way for answering questions that start with “how” (Collins, Onwuegbuzie, & Sutton, 2006, p. 24).

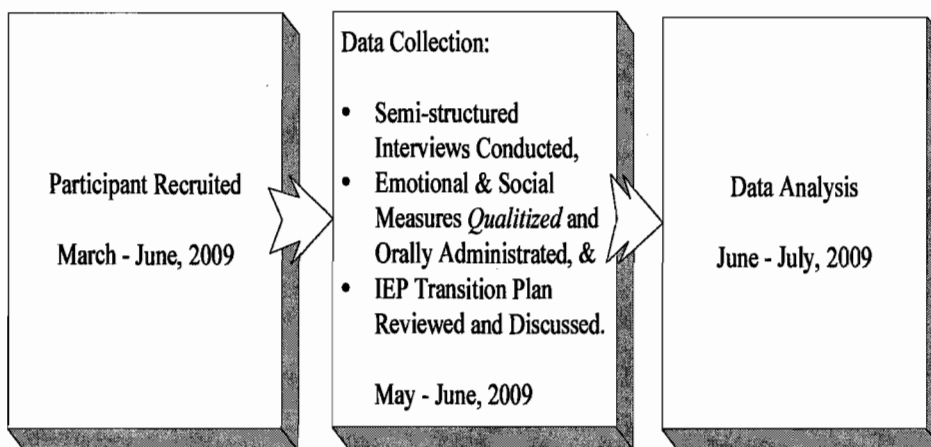
Data collection strategies were focused on gathering information about educational inclusion from the perspectives of students with ID, as the voices of this group of students have not been considered in much of the research. This approach is unique since only a small number of researchers have directly provided students with ID a chance to share their experiences of educational inclusion (Copeland et al., 2002; Bach, 2002; Fisher & Meyer, 2002; Frazee, 2003; Hughes et al., 2000; Hughes et al., 2002; McDonnell et al., 2003). The qualitative component of this study allows for some creative means of obtaining informed assent, as described below, which is an especially critical issue given that this study involved students with ID (Doré, Dion, Wagner, & Brunet, 2002; Kennedy, Cushing, & Itkonen, 1997; Carter, Cushing, Clark, & Kennedy, 2005a; Carter, Hughes, Guth, & Copeland, 2005b; Frazee, 2003; Garrison-Harrell & Kamps, 1997; Lincoln & Denzin, 1998; Haring & Breen, 1992; Snelgrove, 2005). Increasingly, researchers have been adopting more inclusive research methodologies to better understand the social and educational experiences of young adults with ID. For example, the 3Rs (Rights, Respect, and Responsibility) project in the Region of Niagara, Ontario, has adopted various methodologies (e.g., drama, interactive activities) for instructing persons with ID and their

caregivers about their human rights (Owen et al., 2003; Stoner et al., 2002a; Stoner et al., 2002b, Tardif-Williams et al., 2007). The 3Rs methods, like the ones used in this study, shift individuals with ID as dependent participants to active, engaged members in the research whose voices made direct contribution to the knowledge of inclusive education.

Setting and timeframe. Five of six semi-structured interviews with caregivers and students with ID were conducted in their homes and one was conducted at a secure location in one of the Associations for Community Living in the Niagara Region by the researcher and RA. Participants were provided their choice of interview times and locations when they were contacted by the researcher to set up appointments. On the days when the interview was booked at a head office, only the Executive Director knew the interview would be conducted as the Executive Director reserved the space for the interview under the name “appointment.” The appointment was conducted after the agency’s hours of operation to ensure the caregiver’s and her child’s confidentiality. Interviews with caregivers and students with ID for the most part were conducted separately. In some circumstances caregivers wanted to stay with their child during his/her interview, and vice versa. As well, some children wanted to be part of their caregivers’ interview. However, caregivers who expressed a desire for a private interview without their children present were accommodated. Of the six interviews with caregivers, four caregivers chose to include their children in their interviews. Only two caregivers whose spouses participated chose to have their interviews in private. Of the five children who were interviewed, two chose to have their interviews in private and the remaining three wanted their caregivers present during their interview. Because it was possible that caregivers may have wanted to share “negative” issues about their children it was especially important to inform them of their option to have a separate interview to protect them or their children from feeling uncomfortable.

The time frame for data collection is outlined in figure 1.3. The time of recruitment and data collection in this study was specifically designed to take place after students had made their transitions into secondary school and had time to adjust to their new school semester and schedules. Recruitment and data collection started in February, 2009 after Research Ethics Board approval to proceed had been obtained (see Appendix N) and students had returned from their December holidays. Starting recruitment and data collection in February provided time for students with ID to re-establish relationships with their peers with and without ID. Completion of data collection was at the end of June, 2009 and data analysis commenced in July, 2009.

Figure 1.3: Time Frame for Recruitment and Data Collection



Data collection procedures. Triangulation of the data was achieved by collecting multiple sources of data (Berg, 2004). Students with ID and their caregivers were invited to participant in one semi-structured interview each and these were conducted sequentially but in the order specified by the participants. Specifically, caregivers and children were offered the opportunity to decide who would be interviewed first. Providing caregivers and their children with the choice of order for their interview assisted with establishing a sense of comfort with the researcher and

her assistant as it put the participants in control rather than the researcher dictating their participatory expectations. Interviews were conducted from May to June, 2009. During the interviews, quantitative measures (as discussed in the next section; see Appendix K) were orally administered. The quantitative measures served as a reference point in guiding the interview process. Although the quantitative measures are typically used as clinical measures, they were qualitized (Tashakkori & Teddlie, 1998) to enrich the interviewing process for yielding meaningful and relevant responses. Semi-structured interviews with students with ID and their caregivers focused on the perspectives of participants about the transitional experiences of students with ID and the role of educational inclusion in this process. Specifically, students with ID and caregivers were asked to report on social or emotional challenges that were observed or experienced while students with ID were transitioning into secondary school.

Caregivers were asked at the time of their interview to share their children's "Individual Education Plans" (IEP) transitional plans (for a description of IEP transitional plans see bottom of page 47). The transitional plans of students with ID were discussed as part of the caregivers' interviews to determine how they shaped the educational inclusion experiences of students with ID. Caregivers have reported in much of the research that transitional plans were often not adequately developed and implemented to facilitate their children's transition from elementary to secondary school (Gelzheiser, McLane, Meyers, & Pruzek, 1998; Noland et al., 2007; Weber & Bennett, 2004). Including the perspectives of caregivers was helpful for providing additional insight into how students with ID were socially and emotionally affected during their transition to secondary school. The value of including caregivers was especially apparent among children with ID who had challenges with communicating their responses during their interviews; therefore, the caregivers' accounts provided additional and rich data to their children's accounts.

Measures

Three measures were used to collect multiple sources of data for triangulation of the data in this study: 1) Semi-structured interviews were conducted with caregivers and their children with ID where the “Child Behaviour Checklist/6-18 Caregiver Form” (Achenbach, 2001a) and “Youth Self-Report” (Achenbach, 2001c) were orally administered and qualitized (Tashakkori & Teddlie, 1998); 2) students’ school histories were reviewed and discussed with caregivers; and 3) students’ “Individual Education Plans” were reviewed and discussed with caregivers.

Demographic information was not collected because it was considered to not be relevant to the objectives of this study. However, characteristics of the caregivers and their children were collected to give a context for the data analysis. In particular, caregivers’ characteristics included employment, gender(s), and relation to child (e.g., biological, step, grandcaregiver, adoptive, foster, or other). Characteristics of children included type of disability, age, school grade, school history, grade repetition, type of class in grade nine and special education placement/services. Consistent with this study’s research questions, the interviews were mostly focused on students’ educational inclusion and transitional experiences from elementary to secondary settings and their unique social and emotional outcomes.

Semi-structured interviews. Interviews were conducted with students and their caregivers. The interview guides (see Appendix K) were developed to obtain information about students’ school histories and were structured from items on the social and emotional measures (see Appendix K) and the IEP transitional plans (see Appendix K). The social and emotional measures were orally administered and opportunities were taken to discuss items from them, as well as from the IEP transitional plans. Oral administration of the measures assisted with establishing rapport with participants and their caregivers and provided opportunities to probe for

more in-depth responses. As well, probing provided opportunities to ask questions that helped clarify and elaborate children's and caregivers' responses. The structure of the interviews was flexible to permit the researcher to reorder and reword items to adapt to participants' ability to understand and respond (Berg, 2004). The caregivers' interviews unfolded as follows:

1. Caregivers Interview Guide (see Appendix K) that asked about their children's school history and social experiences;
2. "Child Behaviour Checklist/6-18 Caregiver Form" (Achenbach, 2001a; see Appendix K) that was qualitized (Tashakkori & Teddlie, 1998) to examine social and emotional outcomes in-depth during students' transitions to secondary school; and
3. Review and discussion of the students' IEP transitional plans (see Appendix K).

In four of the six interviews, caregivers did not have a copy of their children's IEP but were able to discuss their understanding of what was contained within it as they transitioned into grade nine and refer to them in general in respect to their level of inclusion.

The children's interviews unfolded as follows:

1. Children's with ID Interview Guide (see Appendix K) that incorporated questions about what children liked or disliked about their school when they transitioned to grade nine; and
2. "Youth Self-Report" (Achenbach, 2001c; see Appendix K) that was qualitized (Tashakkori & Teddlie, 1998) to examine social and emotional outcomes in-depth during students' transitions to secondary school.

Considerable effort was undertaken by the researcher and her assistant to ensure children's interviews were shorter than caregivers' to avoid participant fatigue or boredom. On average, the interviews lasted approximately 1 hour for caregivers and 30 minutes for their children.

Social and emotional outcomes. Two measures were used to examine social and emotional outcomes during the transition to secondary school: The YSR (Achenbach, 2001c) and the CBCL/6-18 (Achenbach, 2001a). The YSR was orally administered to students with ID and the CBCL/6-18 was orally administered to caregivers. The YSR and CBCL/6-18 have a “Competence Scale” that yields social ratings of “Social and Academic Activities”. Additionally, each measure has “Problem Scales” that yield emotional ratings of “Withdrawn, Somatic Complaints, Anxious/Depressed, and Social Problems”. Although these measures are quantitative they were qualitized to provide points for discussion during the interview process (Tashakkori & Teddlie, 1998). The measures were developed and tested by the researcher and her assistant to be comprised of items from the measure that were focused on social and emotional outcomes and to stay within the timeframes for the interviews. The same items were administered on both measures in every interview with caregivers and their children. The items used were highlighted (see Appendix K) on both measures to provide a cue to the researcher and her assistant for guiding the interview process. These measures typically are used to rate responses on a likert-type scale and the items vary from “Not True”, “Somewhat or Sometimes True” or “Very True” or “Often True” (Dutra, Campbell, & Westen, 2004). However, the rating scores were not used in the analysis of this study’s data. Rather the responses to the items were used in data analyses that were based on the items being qualitized. Appendix L provides examples of how the items were qualitized and how the responses elicited rich in-depth data.

Transitions. Individual Education Plans. (IEP) are developed to provide educators, caregivers, and students with ID a plan for their educational needs and services for each year that a child is registered in school (Gelzheiser et al., 1998; Ontario Ministry of Education & Training, 1999/2000/2004; Weber & Bennett, 2004). One part of the IEP is a section that addresses

transitional plans that are required by the time a child is 14 years (Ontario Ministry of Education & Training, 1996/1999/2000/2001; Weber & Bennett, 2004). Caregivers and researchers report that goals and objectives for transitional plans are often irrelevant to the social needs of students with ID in terms of preparing them to better navigate community living and/or postsecondary opportunities (Gelzheiser et al., 1998; Noland et al., 2007; Weber & Bennett, 2004). The IEP transitional plans of students with ID were reviewed if caregivers had copies of them and discussed as an additional guide for structuring the interviews with caregivers. In particular, the IEP transitional plans were discussed in terms of what role educational inclusion played during the elementary to secondary school transition experiences of students with ID as they entered grade 9. As well the IEP transitional plans were discussed in relationship to caregivers' aspirations for their children's future after secondary school and the extent to which their plans have addressed their needs for transitioning into their communities or postsecondary school activities.

Data analysis. A similar data-analytic approach was used to examine both students' and caregivers' responses. Interviews were transcribed by RAs and checked for accuracy. Specifically, transcribed interviews that included the oral administration of the questionnaires and IEP transitional plans were open coded and analyzed by the researcher for emergent themes and/or trends in the transitional experiences of students with ID to secondary school and the role of educational inclusion in this process (Berg, 2004). Successive coding was used to further explore and code the data based on the emerging themes and/or trends identified by the research. Once coded, the data were examined for interconnections among the following themes: students' transitional and inclusive educational experiences, educational interdependence, and social and emotional outcomes (Berg, 2004). Particular focus was given to the examination of the unique

social and emotional challenges that some students may have experienced as a function of having experienced an incongruent elementary/secondary school transition (e.g., inclusive elementary to segregated secondary school setting).

Transitional and inclusive educational experiences. Coding for transitional educational experiences was based on students' and caregivers' reports of experiences or activities (e.g., tour of the school, practice being a student before attending full time, etc.) as they moved from elementary to secondary school. Inclusive educational experiences were coded based on students' and caregivers reports of experiences or opportunities (e.g., attending regular classes, attending a school dance, eating lunch in the cafeteria, attending special functions, such as awards ceremonies, joining a school special interest or sports team) when students reported that they were included with their peers with and without ID.

Educational interdependence of social and emotional developmental outcomes. Coding for educational interdependence was based on students' and caregivers' reports of enhanced growth (age appropriate or maturity) in social and emotional outcomes associated with the students' inclusion with peers with and without ID. Students' ages, and their cognitive functioning were considered in relationship to the interpretation of the data.

Unique social challenges. Challenges were examined by coding for negative and positive social outcomes. Negative social outcomes were defined as reports of social rejection, small social networks (few friendships or interactions with peers with and without ID in/outside of school), developmental regression in social behaviours (acting/behaving or displaying behaviours too young for their age), compliance (acting/behaving as prescribed by the expectations of others, such as caregivers, teachers, professionals, etc.), dislikes school (poor attendance or acting in ways to avoid/escape school), and adult orientation (tendency to prefer

socializing with adults rather than similar aged peers with and without ID). Positive social outcomes were defined as reports of social acceptance, large social networks (numerous friendships or interactions with peers with and without ID in/outside of school), developmental growth in social behaviours (acting/behaving or displaying behaviours that were age appropriate), self-determination (acting/behaving as the student feels or wants to rather than as they are prescribed to act/behave by others, such as caregivers', teachers', professionals', etc.), likes school (good attendance or willingness to attend), and peer orientation (tendency to prefer socializing with similar aged peers with and without ID rather than adults).

It is important to note why compliance is coded as a negative social outcome for students with ID. Specifically, research has examined the extent to which persons with ID have been taught by others (caregivers, teachers, professionals, etc.) to behave/act in compliant ways in social relationships as a result of their inherent vulnerabilities (Lord & Hutchinson, 2007; Owen, Sales, Griffiths, & Richards, 2001; Tarulli & Sales, 2009; Tarulli et al., 2004). More pointedly, compliance often results in persons with ID being the inactive agent in a social relationship rather than an active, willing participant in forming social relationships, such as friendships. In the worst cases, compliance has been associated with a long historical precedence of abuse (emotional, physical, financial, and sexual) among persons with ID because self-determination is not fostered among this particular population in association with their inherent vulnerabilities. Inherent vulnerabilities are the exact reasons self-determination should be encouraged among persons with ID to advocate for their rights to be active agents in social relationships.

Unique emotional challenges. Challenges were examined by coding for caregivers' and children's negative and positive emotional outcomes. Negative emotional outcomes were defined as reports of feelings of isolation or loneliness, social anxiety (worrying/nervousness),

depression or sadness (crying, acting out behaviours, aggression, etc.) and fear of school.

Positive emotional outcomes were defined as including reports of feeling a sense of belonging (to school and peers with and without ID), social confidence/competence (willingness to engage in school and with peers with and without ID), happiness/contentment, and enjoying school.

Inter-rater Reliability. To establish inter-rater reliability, the researcher and the RAs both independently coded 20% of the data from all of the children's ($n = 5$) and the caregivers' ($n = 6$) interviews. Inter-rater agreement assisted with establishing the reliability and validity of the data analysis. The second rater was to mitigate possible bias and acceptable agreement values were replicated. Cohen's "Kappa Coefficient" was used to determine inter-rater agreement, and inter-rater agreement was found to be at $K = 0.82$ for the children's data coding and $K = 0.93$ for the caregiver's data coding with an overall $K = 0.88$. A "Kappa Coefficient" greater than $K = 0.61$ to 0.80 is considered to be thought as substantial agreement that is better than chance between raters (Fleiss & Cohen, 1973; Landis & Koch, 1977). Discrepancies in coding were addressed by determining what differences in coding occurred and discussing the rationale for why the researcher and the assistant researcher had coded sections of the data differently.

Chapter 3

Findings

This chapter is divided into two sections. The first section addresses research question #1 and the expected findings associated with this research question. In this case, the goal was to examine the unique social and emotional challenges that students with ID may face as they experience incongruent transitional experiences from inclusive elementary to segregated secondary settings, as compared with their peers who experienced congruent inclusive or segregated elementary-secondary school transitions. The second section addresses research question #2 and the expected findings associated with this research question. In this case, the goal was to examine the critical role that educational inclusion would have during the transition to secondary school among students with ID, with students and caregivers reporting more positive social and emotional outcomes when experiencing more inclusive educational settings. Items from the CBCL and YSR were chosen based on the previous research that pertains to social and emotional outcomes that are related to inclusion/exclusion (e.g. depression, loneliness, size of social networks, etc.). Qualitization of the measures assisted with collecting rich data for expanding established quantitative measures that were designed to focus on social and emotional outcomes but provided the latitude to enrich the interviewing process as demonstrated in the quotes in this chapter. Some words/phrases are bolded to highlight how they clearly articulate students' lived experiences.

Research Questions and Expected Findings

Research question 1.1 and expected findings. Recall that it was expected that the transitional experiences of students with ID who experienced educational inclusion in elementary school and who transitioned to segregated secondary settings would be characterized by greater

negative social and emotional challenges because it was incongruent with their inclusive elementary experiences and thought to be disadvantageous based on the research reviewed earlier. Two students were classified as having incongruent (inclusion/segregation) experiences.

Incongruent (inclusion/segregation) educational experiences: Student C1. One student had an inclusive elementary experience and transitioned into a segregated secondary setting for his core subjects but was provided opportunities for inclusion that were congruent with his elementary experience in less academic subjects, such as physical education, cooking, and auto shop. This student's positive social and emotional outcomes when he had experiences that were congruent with his elementary experience were captured in this quote from his caregiver:

P1: When there's a school dance, he friggin' loves it. If something's going on, you know, we have a function tomorrow, we have this, he knows, like he'll have, a boy-girls Olympic Day or something, he's got his stuff all packed that night, he...

R: And if it's just a day where it's just core subjects?

P1: Yeah, he's like going, but he's like, boo-hoo. He's like worried about what we're going to have for lunch...I mean school itself isn't great for him, he's not a big fan of...

R: The structure of the classroom?

P1: Nope. He's not at all... Yeah, he'll like fall asleep, he's like, yeah, no, he's not into...

This caregiver reported that her son likes going to school when he can engage in activities with all of his peers, with and without disabilities; her son does not like going to school as much on days when he has his core subjects which are segregated and incongruent with his inclusive elementary experiences. Knowing that her son benefited socially and emotionally from an inclusive elementary school experience, this caregiver wanted to ensure that his secondary

school experience would have some congruence with his elementary experiences as he transitioned into secondary school:

P1: Yeah, I really wanted to make sure. I didn't want to segregate him, I didn't want a different cafeteria for him, I didn't want, um, you know different school times, he had to be as much as we could, included ...

The following quotes from this caregiver's interview highlights some of the social and emotional benefits that her son experienced during more inclusive moments (e.g., physical education and cooking classes):

P1: Oh, he loves it [referring to physical education], and they're great in high school now, they keep him in grade 9 and he is still integrated in a regular class, he has not moved up with his [peers]...So he's still meeting new kids coming in, which is a win-win, it's great, so he's still playing basketball, but he hasn't moved on in the sense where he is gonna get killed now at volleyball...In grade 12...it's really working well that way

During the interview with the son of this caregiver, he identified that having congruent experiences made him like school as he was quoted as saying: "Yeah... Uh, I don't like uh don't see my friends". When asked what else he liked about school this student identified cooking class as something he liked and this was one of the classes where he was included in the regular classroom with a team of students with and without ID.

R: What else do you like about school?

C1: My teacher's class.

R: Your teacher?

C1: And cooking... Uh, cookies, uh apple pie.

R: Okay. And you can cook all that by yourself?

C1: A team.

R: Who's on your team?

C1: Me, [2 classmates]

R: Oh, [name of girl he likes] again! Oh! Okay, there's a pattern here!

Examining this student's response it seems that he considered cooking and the team of students he cooked with to be a very positive experience. Specifically, he expressed having close feelings towards one person on his cooking team, and that this was important to him.

With regard to his core subjects, this student's secondary school placement was incongruent with his elementary experience, and his caregiver reported that he would say "boo-hoo" in response to these classes. On the other hand, he would indicate enjoying those classes in which he experienced greater inclusion and social interaction such as cooking and physical education – note that these represented more congruent educational moments for this student. Interestingly, however, this student's incongruent educational experience (inclusive elementary to segregated secondary transition) was not found to be associated with reports of greater negative social and emotional challenges. It appears from the caregiver's and the son's quotes that perhaps the opportunities where this student was included in some regular classes may have mitigated some of the negative social and emotional aspects thought to be associated with educational segregation. Perhaps this student's experience challenges the concept of inclusion as a structured continual space of interactions with peers that has typically been defined in the research as full-time placement or location in the regular classroom. Perhaps any opportunity to interact with other kids allows students to break free from physical space and points towards moments of inclusion – in this case, moments for positive social interactions were more consistent with this student's inclusive elementary experience and seemed to be associated with greater enjoyment of his secondary school experience.

Incongruent (inclusion/segregation) educational experiences: Student P6. The second student who was identified as technically having a congruent experience of segregation-

segregation during his transition from elementary to secondary school was of great interest to examine because of the stark negative social and emotional differences that were experienced by this student, which were largely incongruent with his inclusive education during grades 1 through 6. The unique social and emotional challenges this caregiver reported that her son experienced when he was segregated in grade 6 to 7 and during his transition to grade 9 provides what would appear to be a compelling argument towards ensuring students with ID have more congruent experiences in elementary and secondary school.

The following portion of this caregiver's interview provides an account of how segregation affected her son:

P6: Oh yeah, there was a lot of problems I actually had a lot of issues, actually I had to, [son's name] you saw a deterioration... he started, where, like his whole body, he was losing weight, he developed a drooling, his t-shirts were constantly wet.

This caregiver's account of her son's experience suggests that segregation was associated with immediate developmental regression in her son's behaviours that progressively got worse. This is also highlighted in the following excerpt from her interview, in which she discusses her son's fear of school and his steady social, emotional, and physical decline:

P6: He uh, he actually got to a point **where as soon as the bus got near the [elementary] school, he'd be acting up.** He was acting up at school and uh, I had to actually, I kept going to the school, of course everything was fine. I at that point, took me a year and a half to accumulate enough to go against them uh when it came IPRC [Individual Program Review Committee] time, I refused to sign the IPRC and I uh, they came to the house, I refused to have them uh, the Special, like Ed people from the Board level, I wouldn't meet at the school, I had done enough with them... Like they said from the Board level, look it, you can have anything you want. I said, no, I can't, because I can't feel good, you had to know about what was going on. It took me a year and a half, nearly two years for me to get this and like [student's name], **he was on the verge of a nervous breakdown...**He was throwing up...Everything. It was, I had him at doctors and everything, and it really played, it was very heart-breaking because he couldn't come home and tell me and I said no, I absolutely refuse to have my son go back there.

It was based on this caregiver's experience of her son's negative reaction to segregation that she did not have her son return to the elementary school for grade 8 but instead entered him into secondary school the following year. However the caregiver reported that when he first entered grade 9 "they had him I would say segregated." While educational segregation was congruent with this student's last two years of elementary school experience, his social and emotional experiences continued to be negative as indicated in the following quote by his caregiver:

R: ... um when he started having problems with other kids, was it right away? Or did it take some time before that built up?

P6: I, well I think it started right away. ..Yeah, and he, of course, he didn't want to be in that class, so it, everything started building up and then...naturally...would transfer into [the] next class and keep going on because it was building up because he couldn't get, you know, he didn't feel good...Yeah because they were avoiding him [referring to other students]...And then he started hitting out... I could see changes of like where he was getting what he was when he was at [elementary school], and I kept going, and going... The principal started to threaten me that [son's name] was going to be sent home as a punishment ...

This caregiver's account suggests that the segregated setting that her son transitioned into was eliciting a similar negative social and emotional response from her son. Social rejection, coupled with her son's communication challenges, appeared to make matters progressively worse socially and emotionally; however, the educators' responses were reported by the caregiver to be punitive rather than supportive in facilitating her son's transition into secondary school. According to the caregiver, it was her son's steady decline that resulted in a specialized team of professionals being called in to assist the secondary school in supporting her son in making his transition to secondary school from year-to-year. This team consisted of a psychologist, a speech pathologist, and an occupational therapist who came to assess her son's environment and train his teachers and educational assistants to work with him. The caregiver was quoted as saying about the

specialized team: “So fortunately now we have them and everything’s been turned around. which I’m very happy for, ...”.

In addition to having professional support this caregiver identified in the following excerpt of her interview that having former classmates from his elementary school assisted with ensuring greater congruence in his transition from elementary to secondary school; however, his tendency to rely heavily on their friendship was not ideal:

P6: Well, fortunately, there was some there [former classmates] that he knew from [elementary school], his previous school... So this helped... Otherwise I think it would have maybe been a little bit different... he would basically cling to them a little bit, but obviously they, at first they were happy to see [son’s name] but then, you know, they didn’t want him constantly over, hovering... You know, they wanted their space, I guess that’s what...

As with the first student, this caregiver’s son was integrated into less academic subjects. However, it was not until the end of the school year that this integration happened as the caregiver reported that her son needed time to develop a “trust” and “comfort” in his new school that had been “broken” during his elementary experience.

P6: Well they had to basically build a trust with him. ...Home is like, he knows what’s at home. But it’s the outside world basically that failed him... Like I could work with them, showing him the visuals, being supportive and trying to encourage him ... and reassure him that they’re trying their best, but they basically had to do that trust themselves...I couldn’t build that for them.

Art and physical education classes provided this caregiver’s son with opportunities to be included with students with and without disabilities. These classes were identified as her son’s favourite subjects by both the caregiver and the son:

P6: [calls son’s name]... Do you like art, phys-ed., language?

C6: Phys-Ed.

P6: Art and phys-ed. Okay. He’s in, um, in a regular art ... And the first time he was in the art class uh, I think the teacher, the art teacher talked to the students first, but she’s very strict in her class.

Based on the caregiver's account of her son's experience in art class, the educator in this circumstance created an environment for her son and his peers without disabilities to experience greater educational inclusion. As the interview with this caregiver progressed it became readily apparent that her son's love of art appeared to be one of his forms for communicating. Pieces of his art work were professionally framed and were proudly displayed about his home. Many of the art works that were shared with the researcher and her assistant during the caregiver's interview were alive with vibrant colours of red, green, and blue, and they all seem to suggest vibrant, energetic movement within the world that her son drew or painted. Further, it was her son's art work that provided additional opportunities for inclusion that occurred outside of school, social opportunities about which he was extremely excited:

P6: And you know, I, we got a few of his paintings from the school to observe and you know people to look and I took some of what he's been doing at the art class and I actually, I was quite amazed at the people that came...And ...he loved it...I don't know how long he'll take, you know he may not want to stay there the whole time, but uh he stayed there, he'd go, and people'd shake his hand and...he started doing sketches of people and...

According to this caregiver's account of her son's experience outside of secondary school, her son has the capacity to flourish socially and emotionally when he is provided opportunities to be included. This caregiver also reported that as her son ages he expresses a desire for greater social interaction, a point which is nicely highlighted in the following quote: "And that. ... now that he's changing and he wants to be more sociable, it's, it's something I'm sort of watching."

Interestingly, during our interview with this caregiver her son would interact with the researcher and her assistant. At points throughout the interview he would physically move closer and engage with us in ways that seemed to demonstrate his desire to be a friend, to be social, to be included. The following quote by his caregiver clearly suggested to us, the researchers, that he

was a social being that desired to be included: “[to C6] Did you want to come and sit here with us? Okay you can sit down at the end here.”

However, this caregiver indicated how her son’s desire to be social was juxtaposed with the maturation and changing social experiences of his peers without disabilities, as they transitioned from elementary to secondary school. The following quote highlights how her son’s desire for friendship was not always equally met by his peers:

R: Mhmm. Yeah, and I mean, making friends, like would you say his friendships now are different now from when he was in elementary school?

P6: Oh, very. Very definitely...I would say, from Kindergarten to grade 2, like, kids loved to mingle with him... But as the kids got a little older, and they all get into their own little sets and groups...Because like they’re moved on, they, they’ve made friends and they don’t realize that just because you’ve made friends, that you, they, they changed, you know like these kids still like you know, want to be involved too...And you know but I think the more people are more broadened out, knowledge-wise...And realize that **just because you have a disability doesn’t mean you can’t be a friend.**

On days when her son would have negative experiences at school she would report the emotional toll it would have on her son and her. The following quote by this caregiver highlights the dyadic complexity of the emotional impact that her son’s congruent/incongruent elementary to secondary transitional experience had for both the caregiver and her son:

P6: Uh, to tell you, he would come home and uh he would actually go and lay on the couch and he would cry his eyes out... And, it’s like I said to the school, you know, it’s a terrible thing when your child can’t come home and tell you what’s happened...At school. And you’re trying to find out where you can help them... you can’t, don’t know how to...hel, or help him...And I just try to soothe him and say, I’ll try [son’s name], we’ll try to work this out, we’ll find out. Uh, whether how much of that he really understands, I just think the fact that he knows it’s like he breathes a breath of fresh, of relief.

Clearly this student’s experience stands in stark contrast to the first student’s experience, both of which were classified as incongruent in nature. For this second student, his caregiver’s report provides compelling evidence that considerable efforts may be required from schools to

ensure students with ID have positive social and emotional outcomes as they transition from inclusive elementary to segregated secondary settings. As well, this student's inclusive experiences in secondary school, those which were congruent with his earlier elementary experiences (similar to the experience of the first student) were associated with more positive social and emotional outcomes. It was demonstrated that this student's inclusion experience outside of school seemed to be most beneficial for him and it appeared to facilitate his desire to be socially engaged with people. Clearly, the concept of inclusion as a physical space within a regular classroom begins to take on another meaning when the imposed structure of inclusion appears to be transferrable into moments or experiences that occur beyond the classroom. Moreover, considerable effort was required for this student by his art teacher and his team of specialized supports to ensure inclusive experiences occurred for this student in the classroom that were more congruent with his earlier elementary experience. It was not the classroom per se that appeared to be associated with this student's positive emotional outcomes but rather it seemed that there was a shift in his educators' philosophical approach after training was provided from this student's specialized team of supports and his art teacher's desire to having him included. The most compelling aspect of this student's experience was the extent to which his caregiver shared her son's educational segregation; the dyadic complexity of their shared negative emotional feelings was repeatedly evident throughout this caregiver's interview. This caregiver's account seems to suggest that schools need to form partnerships with caregivers' of students with ID. The notion that caregiver's are the experts of their children's special needs may have facilitated a more congruent experience for her son from the beginning of his transition into secondary school.

Research question 1.2 and expected findings. Recall that chapter one outlined several research questions (and expected findings) based on the existing body of literature. Due to the low response rate, however, it was not possible to explore one of these research questions (i.e., research question 1.2), namely whether more positive social and emotional outcomes would be associated with students' transition experiences from segregation in elementary school to inclusion in secondary school (incongruent (segregation/inclusion) educational experiences). Unfortunately, this study did not identify and include students falling in this latter category, a circumstance which is consistent with previous research findings since students in segregated elementary environments are often reported as having more severe disabilities that are considered to be better supported in segregated secondary school settings (Bélair et al., 2008; Frazee, 2003; Weber & Bennett, 2004).

Research question 1.3 and expected findings. It was expected that students with ID who experienced educational segregation in elementary school and who transitioned to segregated secondary settings will have experienced fewer social and emotional difficulties. This was expected because for these latter students their transitional experiences to secondary school were congruent with their prior educational experiences in elementary school (see figure 1.2). Two students with ID were classified as having congruent segregated elementary to secondary school experiences. Both were provided opportunities to be integrated in less academic subjects, such as physical education, but for the majority of the day these students would be in segregated classroom. The quantity of these students' integration was in classes that occurred less frequently through their daily and weekly schedules than their segregated class time. Specifically, physical education, wood shop, and art were every other day or once a week; whereas, language and math occurred daily.

Congruent educational experiences (segregation/segregation): Student C5. Out of the two students, one appeared to experience a greater level of segregation because he ate his lunch in his segregated classroom. The other student would eat her lunch in an integrated cafeteria. However, according to the caregiver of this latter student, the students with special needs always had educational assistants in the cafeteria with them and they would appear to self-segregate into little groups to eat as the following quote from the caregiver's interview illustrates:

P5: You know, um, but realizing you know after they, they're not, there's always other teachers there... They're never on their own. And...because you have all the kids there, some of the children need to be fed ..., her and her few friends, I think the ones she really groups with, I think there's one, two, about five, five or six of them, just like the rest, they have their own little table and they eat lunch and... Of course kids all sat, you know, just like any high school, the grade 10s there, 9s there, special needs there and the older kids goin', anybody got extra? [laughs] The moochers [laughs]

R: Yeah, yeah. [laughs] So, [to daughter] do you like going to the cafeteria for lunch?

C5: Mmm. [smiles]

Interestingly, although her daughter was technically in grade 10 at the time of this caregiver's interview, she separates her daughter's cafeteria experience into the "special needs" category and indicates that her daughter's friends from her class formed their "own little table". Further probing revealed that her daughter spent her lunch hour in the school and her caregiver was trying to advocate for them to be "allowed" to go outside after their lunch; however, the fear that the students may be bullied was a reason for restricting their access to less supervised areas of the school:

P5: ... I've been trying to see if they can you know go outside, like after lunch sometimes they play cards or they go do something um, I don't know what, maybe clean up the kitchen, you know, whatever, but sometimes I wish they would allow them to go out front of the school, not that I think...yeah, I guess it was the same thing I've, I would've feared for my other children when they moved to another school is, is will they run into a bully?

This caregiver's fear of her daughter being bullied is not unusual and is typically reported among the issues that preclude caregivers from advocating for and placing their children in regular classrooms (Chesley & Calaluce, 1997; Connor & Ferri, 2007; Garrick Duhaney & Salend, 2000; Hilton & Liberty, 1992; Leyser & Kirk, 2004; Rainforth, 2000; Wasburn-Moses, 2006; White, 2002). It is not surprising that the caregiver reports a greater potential for bullying in areas of the school where there is less supervision such as the school yard in this student's case. By keeping students with special needs within the walls of the school educators can provide assurance to this caregiver that "They're [referring to the students with special needs] never on their own." While both students experienced some inclusive educational experiences in physical education, which were incongruent with their segregated experiences in elementary school, reports from some caregivers and children suggest that they experienced social rejection within their inclusive secondary experiences. For example, the quote below from the caregiver whose daughter had lunch in the integrated cafeteria suggests that despite her daughter's placement in a regular gym class, "she wasn't really included":

P5: Yeah, and there again, it depends on how I felt, like she could integrate into uh like this year with the first term she did do phys. ed., um in an integrated class um...

R: So when she went into grade 9 was she um doing phys. ed. then as well or?

P5: Yeah, yeah, 'cause I always chose that...Um, I you know in the beginning to me it was 100% it was very important um but like I said as the years went uh, it's not as, as important, like even... when she was in the, in the gym class, she wasn't included so I didn't like that, because there was, a couple times I had to be there and sometimes the teacher wasn't there and it just, I don't know if they're not, teachers are not taught everything like you know average children, regular, disability, I don't know if that's teachers' choice...

The negative experiences that her daughter experienced within the regular physical education class might be a result of the teacher not providing a truly inclusive learning environment. The

caregiver alludes to her daughter's teacher as lacking the skills about student diversity, skills needed to provide a truly inclusive learning environment. However, despite this experience her daughter reported that she liked school more in grade 10 than she did in grade 9 and this appeared to be a surprise to her caregiver as reflected in this quote by her daughter:

R: Do you like Grade 10?

C5: yes

R: yeah, and did you like grade 9

C5: (Shakes head)

R: no, what didn't you like about grade 9?

P5: You didn't like it last year?

C5: no

P5: what was wrong with last year? What was wrong that you didn't like it?

C5: I don't know

P5: you liked going to school, why didn't you like school?

C5: don't know

R: is it just better this year?

C5: (nods)

R: Yeah, it's better, do you have more friends this year?

C5: (nods)

It seemed during this student's interview that at points when she would identify something that was opposite to her mother's account of her elementary to secondary school experience, such as not liking grade 9 as much as grade 10, the caregiver's response to her daughter's claims seemed to inhibit her daughter's responses during the interview. Interestingly towards the end of this

student's interview the mother had to leave to pick up her daughter and her son was left to supervise his sister's interview from a distance. At this point, her daughter's responses during her interview became richer and more informative as demonstrated by this one excerpt about her friends:

R: About how many times a week do you do things with any friends outside of regular school hours?

C5: Three or more – they go swimming, shopping – they really like Jonas

Brothers

Clearly, this student had friendships and was engaging in social interactions that appeared to be positive because she would smile and appear to be excited about the activities she told us about. As well, her caregiver identified in the excerpt from her interview below that there had been times when she was at school functions with her daughter and her daughter would be greeted by other students that may have been from her integration in physical education or the cafeteria:

P5: So that little get together kind of thing that we had uh, I noticed that a lot of **other students from another part of the school would say hi**. She'd say hi, oh, that's so-and-so, she has met, I don't know through [the] cafeteria, I know they don't, could a been phys. ed. too the one term where she did, which I'm still contemplating on it, whether I'm going to integrate her this year or not and...And anything. You know. She, she didn't even mind it, **she liked it**, so...

Although the caregiver appears to have reservations about her daughter's inclusive secondary experiences, she did seem to observe her daughter had friendships from those experiences and liked being in the regular classes. This student was reported to have been in class for special needs in grade 9; whereas, the caregiver reported her daughter's grade 10 year she tried some integrated streamed classes which included her favourite subject, drama.

Interestingly, the issues pertaining to social rejection were reported by this caregiver to occur more often with her classmates who had special needs. Specifically, this student seem to

be referred to by the caregiver as popular and negotiating shared friendships would be a reoccurring issue for her daughter that the educators would often have to provide support and assist her daughter and her friends with learning how friendship can be shared.

P5: You know like and then there would be sometimes coming home, now so-and-so doesn't want to be my friend, and then she was a little bit disappointed, but like the teachers would say they, they, you know, they'd say we've got a handle on it, we just want you to know, and I said, well that's great...

This latter quote from the caregiver suggests that, not unlike other adolescents, her daughter was learning valuable social skills that would assist her as she matured. Conflict will occur in social relationships and the ability to resolve it is a social skill that will provide this student with the foundations for healthy, respectful social relationships.

Congruent educational experiences (segregation/segregation): Student C2b. Unlike the first student, the second student's congruent elementary to secondary transitional experience was characterized by more segregation, educational or peer supervision, and social rejection. The caregiver reported that the only time her son was in a regular class was during physical education and he experienced integration during school assemblies. Further, the caregiver indicated that her one son does enjoy attending gym but that being included is something her son needs to get used to and that while he is exposed to his peers without disabilities "they may make comments, but that's typical of people." Such "negative" comments were further identified by the son during his interview as being a source of conflict while he was included at school because he would experience social difficulties when other students at school were being "rude" to him. Interestingly, the caregiver suggested that her son is not aware of other students' "intentions" by stating that "they don't know half of what goes on" and she provides her son with social guidance by encouraging him to "just ignore the comments." However, it seems that her son does have some awareness of and difficulty dealing with social rejection.

Despite the reports of social rejection experienced by her son, she did report that he had a social network of friends that included a past and current special relationship with a girl, as reflected in the following quote:

P2a: That's actually a good question [referring to question about friendships].

P2b: With [son's name], whoever is at school... It would be, um, [name of friend], well there's [friend] too, yeah there's [friend]. I forgot that there's [friend]. He's track and field. His girlfriend [name]... [current girl friend], um [name of former girl friend] and that was his former girlfriend in public school.

Although her son did not discuss his special relationship with a girl, he did confirm in the excerpt below that he has friends and that they eat lunch and go to classes together, thus suggesting that his friends would be students with disabilities. However, when asked if he saw his friends outside of school he responded "no." In contrast, the caregiver indicated that her son appears to always be with other students that he knows from his mostly segregated classes, as reflected in the following quote:

R: Does [son's name] complain about being lonely?

P2b: No. There's always somebody around with them.

R: Yeah and is that usually that, uh, when, an adult, like an educational...

P2b: No. Another student... Yup, there's usually students around them... There's, that's just the way the classes are. They just sort of hang around the people they know... The people they know, that's the one's they stick around with.

The student, however, indicated that he experienced some reservations when he started at his new secondary school:

R: Is there any time when you first started school that you felt kinda lonely or that it wasn't for you?

C2b: I guess one time... I guess when I was in grade nine, then... I guess I didn't really like it. At first.

R: And then what made it change? What made you like it?

C2b: I guess when I got to know the teachers and the EA's that are in there.

Proximity to his classmates appeared to be an important issue in fostering the development of natural friendships between this student and his classmates. However, this student identified his relationships with his teachers and educational assistants as the reason he liked school when he first entered grade 9.

For the most part, this student (C2b) reported that he enjoyed school, as reflected in the following quote: "I guess I like it how they uh, have different, uh, classes for what we can do." This student's experience while training for Special Olympics strongly suggests that he was able to speak up for himself as he would let his caregivers know. For example, he immediately objected to being denied access to training in power lifting (to prepare for the Special Olympics). Based on this, it is likely that he would be able to recognize educational segregation as being negative and he did not feel this way at school. Rather, this student's interview responses suggested that he enjoyed school because he was learning and he liked spending time with his classmates despite some experiences of social rejection. When faced with social rejection the caregivers identified that their son would have obvious negative emotional reactions, as described below:

P2b: You could tell by [his] face what type of day [he'd] had, if it was a good day, or bad day... You'd actually look at [his] face, [laughs] if somebody's been bugging [him] too much...

With reassurance from his caregivers, this student appeared during his interview to be able to take his caregivers' advice, as expressed below:

P2b: I said, you probably can do better than they can, that's why. That's what I say. I tell them, just ignore them. They think they know it all. I said but they don't. I said just close your ears off to 'em.

This student's experience as he entered a segregated secondary school was congruent with his elementary experience. When provided opportunities for learning in less academic subjects such as physical education, he was reported by his caregivers to like it. However, this latter kind of social inclusion was reported to also be related to a certain degree of social rejection because other students were "rude." For this student, this kind of social rejection was associated with him having a "bad day" when "somebody would be bugging him too much."

Despite these experiences of social rejection, during moments of educational inclusion (which were incongruous with his elementary school experience) this student reported liking school and having friends within his class. In examining this student's educational experience, one can suggest that a sense of belonging is intrinsic to a student's lived experience, which breaks free from the often held assumption that physical structures such as placement within a regular classroom is key to successful educational inclusion. It seems the uniqueness of this student's experiences when compared to the other students' experiences comes closest to defining inclusion as being about individual experience rather than a universal experience that is grounded in the physical space of the regular classroom. Experiences of inclusive interactions rather than space or proximity seem to be associated with a sense of belonging or exclusion. Although this student was segregated, he did have a sense of belonging to his school and it was not contingent upon his placement in a regular classroom. When faced with segregation outside of school, this student clearly demonstrated his negative emotional reaction to that experience of being denied access to what rightfully he should have been entitled to. However, inherent in messages that he should "ignore" the social rejection and avoid conflict is the notion of compliance, which might be associated with difficulties later in life (e.g., failure to recognize and exercise rights in future social relationships and employment opportunities). Avoiding conflict

and ignoring negative social interactions may provide caregivers and their children with means for coping with social rejection in the short-term; however, it fails to provide students with skills for self-determination and independence for the long-term into adulthood. Without these valuable skills it may result in students with ID having their rights usurped in adulthood.

Research question 1.4 and expected findings. It was expected that students with ID who experienced educational inclusion in elementary school and who transitioned to inclusive secondary settings would report experiencing some degree of social and emotional adjustment but would for the most part report experiencing positive social and emotional outcomes because it was congruent with their inclusive elementary experiences and thought to be advantageous based on the research reviewed earlier (see figure 1.2).

Congruent educational experiences (inclusion/inclusion): Students C3 and C4. Two students, both females, were classified as having congruent inclusive-inclusive elementary to secondary school transitions. Interestingly, these two females were the oldest participants and they attended the same faith-based secondary school. A shared, and unexpected, aspect of these students' experiences is that they reported struggling with their differences when interacting with their peers without disabilities. One caregiver was quoted as saying:

P3a: Um, I think she, she struggles with part of being a regular crowd, you know what I mean?...Yeah. It bothers her, yeah. Um, that's why we get her involved in Special Olympics so she has, has a lot of friends there. And I mean she has friends at school but, they're, it doesn't go beyond school. Um, within learning strategies it does, but...

To address their daughter's struggles with fitting in they encouraged her to participate in activities outside of school such as Special Olympics that would foster a sense of belonging, as compared with her experiences at school when she would engage in social comparison with her "more popular" peers without disabilities. Similarly, the other caregiver had this to say about her

daughter's sometimes negative social experiences (which were confirmed below by her daughter):

P4: ... I do remember her saying that she noticed that she wasn't able to talk to the other, like her grade 8 friends... Like that's what she missed a bit because you know, you go from a, you know she was in a class with like, I don't know what, 30 kids that she knew... That she had gone all the way through with, then you go into a high school where there's all kinds of, you know, you're spread out all over the place... So that part she would say, oh she wishes she could talk to them and they might not be as attentive.

C4: I still don't know why some of them wouldn't talk to me.

P4: What would happen, what happened? Like in the cafeteria? Did you, I remember you telling me this, **sometimes you'd go over and talk to them and they were kinda busy, right?**

It is noteworthy these two caregivers reported such negative social and emotional occurrences as being relatively rare, as compared with the many positive experiences their daughters had.

Interesting, however, of the 5 student participants, these two students appeared to be at a higher level of functioning and awareness as this quote from one caregiver suggests, "Yeah. There was a point there where she, where we almost felt that she was almost advanced enough to be too aware...she was aware enough of the differences that she became more conscious of it..." For these two girls, it is possible that being in physical proximity to their peers without disabilities might have prompted them to question why they were different, as reflected in the following excerpt from one of the girl's caregivers:

P4: No just um just I guess knowing, you know, uh I can't think of one of the days occurred, but I think it has occurred a couple of times anyways where you know, she's wondered why she was born with [name of disability], that sort of thing. Eh [daughter's name]?

C4: Yup.

P4: And she's just kind of asked that question... You know kind of, 'why-me?' type thing?

C4: Did you, were, did you feel that way too?

RA: I still do sometimes.

C4: Yeah.

In contrast, the other caregivers tried to articulate and understand how their daughter's "difference" might have been associated with their daughter not desiring to be included during physical education class despite her athletic prowess:

P3b: I think it was a little bit on the physical education side of things which was kind of confusing to us because she's very athletic [referring to her Special Olympics and medals] but when it came to doing physical education at school she wasn't always the most eager participant.

P3a: She found a way to sit out, or maybe not get changed, I don't know.

P3b: It could've been just that, you know, the group of girls that she was with or whatever it was she was more self-conscious when it came to physical education.

P3a: She would end up sitting out a lot. We never could understand.

The daughter of this couple reported having won gold medals for swimming and feeling so proud of her friends for having done "amazing," and her one caregiver indicated the following:

"Special Olympics you can grab anybody, everybody's happy to help out." Here again is an example when the meaning of inclusion transcended the physical structure and nature of the regular classroom. More pointedly, this daughter's caregiver purposely involved their daughter in Special Olympics "just [to] always keep her busy...but we try and keep her stimulated and involved in other ways so she doesn't have to feel that [lonely] and maybe it's just a mechanism that I've developed over the years."

It was during moments of interactions with friends that this daughter reported having a "good day" as this excerpt from her interview suggests:

C3: Of a good day, um, like all my friends are like, depends on how many friends I talk to in the course of a day at school, I just say, hey, like what's up, I talk like

one word and the they're off theThat's a good day for me... You know? And there's nothing like being in the hall, talking to a friend, it really makes my day.

Not unlike the reports of other students in this study, this student reported that as her time in secondary school progressed beyond grade 9 a bad day would be characterized by social rejection:

R: Okay. So did you find at any time that you've felt like you didn't fit in um when you first got there?

C3: Not when I first got there...As I um, like grade 10, probably grade 11, grade 12 and up, and like my last year, probably a little bit but not too much... Well, when I say, when there's days where **I don't have a good day... feel like they are going not like out of their way, like they're being rude...But um when they just snicker, you know, that, behind my back, but...**

Interestingly, both sets of caregivers and daughters reported subtle or subversive forms of social rejection, which one daughter indicated was likely due to the school's policy against bullying which included cameras for monitoring students' behaviours in all areas of the school. In contrast, the other daughter reported having been physically bullied in grade eight and the secondary school's anti-bullying policy gave her a sense of belonging:

C3: Just feelings. From being bullied going into grade 9, I just thought that I was crying, like you know, like when I was being bullied, they'd kick my shins... And being followed around every step behind, I'd hear my name, they'd kick my shoes...But you know, in grade 9, I, there was none of that...Cause having, high school has a very high tolerance for bullying... And I kind of thought, this, this, this is the school for me.

Similar sentiments were shared by the other daughter and her caregiver regarding the experience of transitioning to grade nine and the freedom coupled with acceptance being related back to this student's opportunities for growth and maturity:

C4: I like the people that I was with...Um, I like the, the, the classes that I took

P4: It was more just that it was um a better environment for her. Uh, it wasn't as uh, I think in elementary you know, there, there's a lot of um emphasis placed on um you know, kind of keeping everybody like this...And ... once she hit high

school, she had um, freedom to go to classes, she was allowed more freedom to do more things. Like she could eventually, eventually she just went about her business doing it on her own. And I think that really helped her to grow and mature... Yeah, it uh, I would say it uh I think, I don't know, it was just a better environment for [daughter's name]. It was um she had more freedom... I'd say there was a lot more acceptance.

However, for this one student her desire for freedom and self-determination appeared to be met with opposition from her educators as this excerpt from her interview seems to suggest:

C4: Yeah. There was one time where an EA asked me to do um to give, she wanted my yearbook and I told her no because I just didn't want to do it... 'cause I didn't trust her...

R: Okay. Yeah. What was it about her that you didn't trust?

C4: I don't know, that she would do something, but... She's embarrassed me a few times.

R: Did you ever say to her, I don't like you doing that, or?

C4: I just didn't have the chance to, I guess... I didn't tell the teachers because you know, like there was one time where she embarrassed me in front of the [name of activity] and you know, she, she didn't, I, she didn't, I didn't tell, like the other EA's didn't know, it was just her and I.

This student's account of being embarrassed by her educational assistant seems to suggest the lasting impression that negative social interactions and experiences can have on students. Across many of the interviews in this study, educators and the school's culture were cited by caregivers and their children as paramount to positive transitions into secondary school. Although the above student reported having difficulty with one educational assistant, for the most part she had this to say about her school mates: "Yeah, a lot of the kids were really nice... No one was ever been mean to me which is good."

These two students' propensity towards making social comparisons between themselves and their peers without disabilities might have led them to question why they were different and why they were not always somebody's friend – thus explaining why their experiences stand in

contrast to the researcher's expectations. As well, despite anti-bullying policies at their secondary school, these students did experience subversive or indirect forms of social rejection that based on the student's accounts made them feel as though they did not "fit in." What seems to be in line with the expected findings is that, for the most part, these students' experiences were socially and emotionally positive (reported having friends) and this might have been due to having congruent educational environments (inclusion/inclusion). However, a sense of belonging or being included did not seem to be contingent upon the physical structure within the space of the regular classroom. In some circumstances students reported that they experienced greater social and emotional satisfaction from being included in activities that were outside of school such as Special Olympics.

Research question 2 and expected findings. It was expected that educational inclusion would play a critical role during the transition to secondary school among students with ID, with students' and caregivers' reporting more positive social and emotional outcomes when experiencing more inclusive educational settings (see figure 1.2). Interestingly, the findings from this study do not provide strong support for this latter expectation. Rather, the results seem to suggest that a lot of interaction with students' peers without ID might be associated with disappointment outside of the classroom when the friendships are not reciprocated, as reflected in the following quote by one caregiver:

P3a: Yeah, mmmm. Yeah, usually, I don't know, like she'll say to me, sometimes I just don't feel like I fit in or um, that kind of thing or...

P3b: And that's usually it. About fitting in.

P3a: Because I think she's struggling with maybe got turned away, or one thing that just um, 'cause I think it was in culinary class, there was a lot of interaction with other kids and then...But then outside the classroom? There wasn't that. So she was expecting the same, a little bit more and she was trying to make arrangements and things just didn't gel.

This student's caregivers surmised that perhaps their daughter was being "unrealistic" and "misinterpreted" some of her peers, who they referred to as the "popular" kids' politeness as friendship because their daughter was reported as perceiving them as her best friends; however, the one caregiver reported: "... but then they'll never call her, or...." When faced with rejection, this student, when compared to the other students in this study, was reported to be confused about why these popular kids were not her friends and her desire for these friendships seem to have more value than those "other kids [who] would be calling her."

Although the daughter alluded to her desire for friendships, she did not directly share her desire for a preferred friendship with popular kids during her interview. Instead, she had a tendency to focus on the positive social and emotional experiences she had since entering secondary school. She would say to the researcher that her experiences with her peers were "amazing, incredible, awesome, and fun." It is important to note that this student was anticipating graduating and reported:

C3: I've never been so excited for this part in my life [laughs]...I've been so ready for grad...

R: Why, why do you think you're so excited?

C3: Well, even though I am coming back for one more year, um, I thought this year, this year'd be my final year but um grad coming up, it means, it tells me that you've, you've just did amazingly well over any part of your life and it's just a step, more, more, more a stepping stone that I've achieved.

This student's sense of educational accomplishment was apparent throughout her interview and perhaps her anticipation of taking on a leadership role as a peer tutor when she returned to secondary school after graduating separated her from the experiences with her peers in the past. She seems to focus on her new role as her "time to shine, to give back" and be more mature. When asked if this would separate her from the other kids she replied, "Being more like of a,

adult about it.” As well, this student had aspirations of attending college. Her caregivers’ efforts to have her attend college did not work out but her hopes for having a second chance at meeting new people was apparent in this excerpt from her interview:

C3: Um yeah, um, it’s gonna be me able to communicate better and seeking new people and meeting new friends is where I want to go...Um, just because, I’m, I’m I love high school and everything about it but now it comes to a point where you’re about to move on and about to leave high school, it gives me a sec, just a second chance to, second chance to like meet new people

When this student was asked why she felt college would be better than when she first went to grade nine she stated: “Um, because you’ll meet new people and meet new friends and **they’re not going to judge you.**” The bolded portion of this student’s response is highlighted here because her facial response during the interview shifted momentarily in a way that it seem to suggest she had said something that perhaps made her feel uncomfortable. Perhaps her response may have subtly alluded to what her parents were referring to how she felt when she desired certain friendships but they were not reciprocated. This same student’s desires for preferred friendships with popular kids seemed to be associated with her rejecting other friendship opportunities.

Educational Interdependence

In some educational environments, students with ID are perceived as dependent because of their needs rather than as part of a whole community that benefits from including and needing each other (Allan, 1997/2006; Lord & Hutchison, 2007; Shevlin & Mona O’Moore, 2000). It can be argued that all students have needs that require some level of support, and from this perspective interdependence among students refers to the mutual support and social/emotional benefit that is achieved through reciprocity in relationships (Shevlin & Mona O’Moore, 2000).

All five students and one caregiver reported that they, or their son, experienced some form of educational inclusion in grade nine. Typically, for most students the inclusion was usually in less academic subjects, such as art, physical education, drama, cooking and auto shop, and in some circumstances students were supported by an educational assistant during their educational inclusion experiences. For the most part caregivers reported that their children and their peers without ID socially benefited from their educational inclusion as the following excerpt from one caregiver's interview suggests:

P1: Oh, I know. I thank my lucky stars every day! [laughs] I am. And you know what though? Like I mean with him playing basketball, that was not me, that was totally the coach saying, he's going on in the last minute of every game...The kids would stand up and go, c'mon [son's name], like, **the kids want him**. I didn't do that.

R: Okay. So, how important is it to you that [son's name] is part of the regular classes?

P1: Huge, his social skills would not be where he is if he was not included in a classroom...Yeah so I think that's what's important because **socially its kept him in the community** where he doesn't get stared at because [he's] included now, because of what, yeah now

This caregiver's report seems to suggest that her son's educational inclusion resulted in positive social outcomes for her son because of his increased social skills and the other kids desire to include him and cheer him as a member of their team.

For another caregiver her son's inclusion in the regular classroom, in this case art, was a learning opportunity for not only her son but for those students in his class without disabilities. This caregiver reported that inclusion may provide a learning opportunity for students without disabilities to develop "better attitudes towards people with disabilities," as outlined in the following excerpt:

P6: I think it's very important for a couple of reasons. I think it's good for the regular students...Uh, educate them...Because they're going to be the future people that are, maybe they'll have a better attitude with people with

disabilities...And I think it's a way of him seeing proper behaviour... because [son's name] is very much a visual learner.

This caregiver's account of the benefits of inclusion seems to suggest a reciprocal benefit for including her son in the regular classroom when she refers to her son benefiting socially from his peers behaviour while they learn acceptance of all people. Interestingly, this caregiver reported that her son's art teacher felt her son's inclusion would serve as a model for other students who may struggle with their abilities to be creative as the following excerpt suggests:

P6: And that and uh the art teacher thinks he's a great, uh, you know great um, uh, how should I put it? She thinks that he's great for the students' morale...Because if they can see what someone with [name of disability] can do in art, to not be discouraged, that they can do something good, too...And I think people all need to realize that they all have a right to be out there. But I want to say that the students at [son's high school] are very open to these students because they're very much a part of that school.

Some caregivers referred to their son's inclusion as a part of life that they would have to get used to or prepare them for the outside world. But in this case the caregivers did not seem to suggest their child's inclusion would benefit other students without disabilities.

P2b: I'd want them mixed in with the other kids...

P2a: That's part of life...They gotta get used to it.

P2b: I would think it's provided them quite a bit for them so they know what the outside world is going to be like.

It was this caregiver's son who stated what benefit they would get from their classmates assisting them with their learning: "I guess, uh, showing us the proper way to do it or something."

Another caregiver stated:

P3b: ... It's preparing her to live as independently as she possibly can and that means not necessarily protecting her from all that, you know, the things that she can face when she's independent. So to have her not integrated, you know, in education or whatever else she does, doesn't really do anything for her when she's an adult in that respect.

Like the last set of caregivers, this caregiver's response seems to suggest that his daughter benefitted more from being included than perhaps her peers without disabilities did; specifically, that being exposed to things such as social rejection will better prepare his daughter for living independently as an adult. His daughter said this about her freedom as she transitioned into grade nine:

C3: It's giving us a little bit of freedom, a little bit.

R: Do you like having that freedom?

C3: Yeah, now I do. At first, like, I, at this age... Yes, I do... In grade 9 I thought I needed the EA support... As I grew up, eventually this was going to happen

Interestingly, this student's response seems to suggest that her experience when she entered grade nine was one in which she felt she needed to be dependent; however, the freedom that she experienced in an inclusive-inclusive secondary school transition seemed to facilitate her growth. Her peer in this study who attended the same school reported a similar experience that seems to suggest her inclusion helped her to grow: "Yeah, I really do. I see my friends there and... We're all in learning strategies all together... And then like I have friends outside that and from there it help me grew."

The following caregiver's response seems to suggest, like some previous caregivers, that her daughter socially benefitted from her inclusion; however, it does not seem to suggest that her inclusion was socially beneficial for her peers without disabilities:

P4: Um I, I would, she'd, she's always been with her peers, right?

C4: Yeah.

P4: And uh you know I just couldn't imagine why would you do it differently now?... I mean, I recognized that you know, the options are somewhat limited to a certain degree because we're faced with that now... But uh at the same time, ... she's very much a social person and uh she loves people... And that's where **she needed to be.**

It seems that this caregiver perceives her daughter as more dependent on her peers providing her with her need for social interactions and this seemed to be mimicked in her daughter's response as well when she stated it helped her to grow.

It was this caregiver's response that captured her daughter's educational secondary experience as affecting all students in a way that they depend on each other as a family:

P5: Yeah so she, you know, nobody's treated, **no everybody's the same there. It's, it's, they, they almost like I feel it's becoming a family** so you know another five years from now you think oh my god, this is going to be hard to leave.

It appears from all the caregivers' responses that they felt their sons and daughters socially and emotionally benefited from being included in the regular classroom. However, in some circumstances, the negative experiences that some students experienced, such as social rejection and having to learn how to cope with it, were cited as necessary for later successful integration in the work place or within social relationships.

Summary of Findings

C3: ... when **I came into grade 9**, it was more, **you've grown up, you've moved on with your life, you made new friends** and once I got, started warming up 'cause they had a dance for all the grade 8's.....going into grade nine, and **I started dancing with a whole circle around me** [laughs] and **from then on it's just been amazing**. Like, I'm, **I made so many friends and it's just been an amazing** couple years in in, in high school.

As the above quote from one of the students suggests, the transition to secondary from elementary school for her seem to be a major event in her life and in the lives of her caregivers. Events of transitioning were often associated with caregivers having to engage in considerable efforts to prepare their children for the transition. For the most part, caregivers and their children reported, that the transition to secondary school was a positive emotional experience. Interestingly, students who had congruent (inclusive/inclusive) transitional experiences reported

experiencing some difficulty in adjusting socially to their new schools (e.g., engaging in social comparisons to try and understand why they were different and why other students would not be their friends). To what extent these students were experiencing similar social and emotional outcomes during their transitional experiences in comparison to their peers without ID may be of interest to examine in future research.

Of the two students who had incongruent transitional experiences, one was reported by his caregiver to have negative social and emotional outcomes as he transitioned to his new secondary school. She reported his experience to be a carry over effect from her son being segregated during his last two years of elementary school and the secondary educators' lack of training and willingness to listen to her regarding her son's needs. Once supports were put in place for her son, his transitional experience was reported to be positive and his caregiver indicated that his peers were "very open" to her son. The two students who had congruent segregated-segregated transitional experiences reported that they liked school and experienced some social rejection when other students made comments, were rude or ignored them, but that they reported having friends and enjoying being part of their school. Generally, most of the students' ($n = 4$) reported, as the quotes from three of the students below suggest, that they were unsure or nervous about their transition to grade nine; however, they all reported that once they started school, got to know their teachers and the other students, their fears were alleviated and they felt comfortable.

C2b: Probably because **I was nervous** or something...

C3: Um, with grade nine when I first started, um, **I thought it would be hard to adjust um**, but now when I look back and being in grade 12, I can really now say that I've grown up... Um, **I wasn't sure** what um like how big the school was going to be. Or how many people it had, or what, what the day's going to bring or...

C3: Um some days. Some days I put on a brave face, a big happy face saying I'm going to go out with my, my, my, my head held high.

C4: Um, I wasn't sure what um like how big the school was going to be. Or how many people it had, or what, what the day's going to bring or...

The extent to which the IEP transitional plans provided additional planning and support for student's transitions was not easily determined. Only two of the six caregivers were able to provide copies of their children's IEP transitional plans and they were either for the current school year or the previous year, 2008. The transitional plans that were seen were one to two sentences in length and were either life skills or academically focused. All six caregivers appeared to be unaware of the transitional plans that were required by law to be in place by the time their children were 14 years or over (Education Act, Reg. 181/98). Two of the caregivers reported that their children's IEP was on a year-to-year basis because they both were quoted as saying "we are waiting to see what his/her capabilities will be" and considering transitional options at this stage might be "disappointing."

The quote from one student below seems to capture the nature of every student's transitional experiences in this study. Although there were commonalities between the students' transitional pathways, there were differences that were unique to the individual and all the students appeared to be in the schools they wanted to be in as long as their social and emotional needs were being met.

C3: And just, **my path for me, or for other people, it's different.** Because people, well my, other people get into high-tech courses because they're so smart but it **doesn't matter how smart you are doesn't matter what your intelligence is just that your heart is somewhere that you want to be.**

Chapter 4

Discussion

The purpose of this study was to provide students with ID who attended inclusive and segregated elementary schools the opportunity to share how their transitional experiences in secondary school impacted them both socially and emotionally, and to explore the role of educational inclusion in this process. Few researchers have focused specifically on the social and emotional impact of transitional experiences among students with ID. In this study, students with ID who were educated alongside their peers in elementary school and then transitioned into segregated secondary settings were examined for potentially unique social and emotional challenges, as compared with their peers who experienced inclusive or segregated elementary-secondary school transitions. It was expected that the transitional elementary-secondary experiences of students with ID that were incongruent with their inclusive elementary experiences, and thought to be disadvantageous based on the research reviewed earlier, would be associated with students and caregivers reporting greater negative social and emotional challenges as their children transitioned into secondary school.

The student who was identified in this study as having an incongruent transitional (see P6 figure 1.2) experience that stood in contrast to the other students' transitional experiences provides a compelling example of the negative social and emotional outcomes and the role that educational inclusion had in the process of this student's transitioning. The findings seem to suggest that considerable efforts may be required by schools to ensure students with ID have relevant transitional planning in place before transitioning from inclusive elementary to segregated secondary educational environments. It was not the classroom per se that appeared to be associated with this student's eventual positive social and emotional outcomes but rather it

seemed that there was a shift in his educators' philosophical approach after training was provided by this student's specialized team of supports and his art teacher's desire to have him included.

Schools who were cited by caregivers and their children as welcoming places with educators who had inclusive philosophies or knowledge of their children's disabilities appeared to be a major catalyst in the transitional experiences of students in this study. All students in this study were provided various opportunities for inclusive educational experiences in secondary school, and all students (whether they had congruent or incongruent educational experiences) reported these as their experiences. Perhaps schools that were providing more inclusive opportunities, such as C3 and C4's schools may assist other schools in developing greater opportunities for inclusion. As well, P6's accounts of her son's experiences provide compelling evidence that specialized supports are an important for assisting schools and educators with fostering inclusion. However, some caregivers reported that they had to advocate for their children so that they could be provided with inclusive educational experiences, or so that specialized teams could be brought in to ensure that their children's secondary school experiences could be planned in congruence with their elementary school experiences.

A surprising finding in this study was the negative social and emotional experiences of students with ID who had congruent inclusive-inclusive transitional experiences from elementary to secondary school. What seemed most compelling was the degree to which these students engaged in social comparisons with their peers without ID. Although there were reports of social rejection from the majority of students, it was apparent during their interviews that level of cognitive function played a role in these students' reactions to social rejection. Specifically, the students who appeared to be at a higher level of cognitive functioning seem to be able to articulate their emotional reactions to their social rejection in terms of their disability, which

might have been associated with them questioning why they were different and why others would reject them as a friend. The extent to which these students' emotional reactions were strikingly different from the experiences of students without disabilities warrants further investigation. Though comparisons would be facilitated by a larger sample, mitigating factors, such as gender, age, socioeconomic status, peers, type of disability, cognitive functioning, school cultures, and educators' skills and philosophies would need to be considered in future research. However, it was the purpose of this study to focus solely on the voices of students with ID and their experiences. Including a comparison group of students without a disability to expand on the findings of this research would provide further insight into the negative social and emotional outcomes for this group of students, as a result of their inclusion. Future researchers need to maintain and increase the active role of students with ID in the research to assist with building the knowledge for and about them.

As well, future research about the transitional experiences of students with ID and the role of inclusion during that process should consider recruitment methods that would involve FSW contacting the families directly for the initial recruitment rather than just for follow up. In this study, based on observed increases in participants contacting the researcher after the FSW conducted follow up phone calls, it might have been more effective including FSW in the initial recruitment to increase the likelihood that a more representative sample would have been used in this study for making comparisons

In this study, the extent to which caregivers and their children reported that their children's social and emotional growth were enhanced because they were included with their peers with and without ID speaks to the social and emotional developmental advantages that have been associated with inclusion (Anderson, 2006; Cohen, Forgan, Klinger, Schumm, &

Vaughn, 1998; Copeland et al., 2002; Copeland et al., 2004; Fisher & Meyer, 2002, Frazee, 2003; Helmstetter, Curry, Brennan, & Sampson-Saul, 1998; McDonnell et al., 2003; Peck, Donaldson, & Pezzoli, 1990; Peetsma, Veger, Roeleveld, & Karsten, 2001). However, many caregivers and their children reported needing or being dependent on others for their social and emotional growth. Educational interdependence was observed in two caregivers' reports about their sons and peers without ID benefiting socially and emotionally from inclusion. The findings in this study suggest that students have needs that require some level of support, and educational interdependence seem to occur when students and their caregivers reported that they had opportunities to interact and be included in social relationships in and out of school (Shevlin & Mona O'Moore, 2000).

In addition to educational interdependence, an unexpected finding of this study was that caregivers reported the "benefits" of negative social experiences. The extent to which all the children in this study were unintentionally being taught compliance out of love and protection by those who care and support them during negative social and emotional experiences when students appeared to be faced with rejection could potentially result in these students with ID being complacent in adulthood (Lord & Hutchinson, 2007; Owen, Sales, Griffiths, & Richards, 2001; Tarulli & Sales, 2009; Tarulli et al., 2004). Compliance is a serious issue among persons with disabilities and the findings from this study seem to suggest that families and their children would benefit from rights education, such as the 3Rs project referenced earlier. Specifically, families need to understand ways to provide support and guidance that will not unintentionally result in their children developing compliance as a reaction to negative social circumstances and students with ID need to be taught they have rights that often play out during their social interactions with other people.

Many caregivers and their children reported their involvement and inclusion in extra-curricular activities were often a way of mitigating the impact of social rejection in school. Special Olympics and personal hobbies (art) provided a means for students with ID, in this study, to experience a sense of belonging that clearly appeared to challenge the concept of inclusion as an imposed structure in a physical space within a regular classroom. Inclusion based on findings in this study seem to suggest that inclusion was intrinsic to the individual's lived experience and could take on another meaning when the imposed structure of inclusion appeared to be transferrable into moments or experiences that occurred beyond the classroom. It was the interchanges between the RA, who had a visible disability, and some of the participants that provided confirmation that they were not alone with their feelings and that she had a shared common experience. It was in this moment that inclusion resided between the interactions of individuals that defied physical space and transcended to a higher experience. This moment of dialogue and experience could not be physically contained but was free from imposed structures or definitions of what it means to be included or having a sense of belonging. Research on inclusion perhaps needs to re-examine what it means to be educationally included. The findings from this study seems to suggest that meaningful educational inclusion transcends the physical boundaries of the regular classroom and occurs rather in real time moments or interactions among all students, with or without ID.

What was most apparent from this study's findings was the importance that caregivers have in their children's lives. Caregivers reported having played a large role in their children's transitional experiences to secondary school. Caregivers and their children reported having opportunities to explore secondary school options/programs and engage in "tours, practicing, and planning" for their children's transition to secondary. Caregiver support, and perceiving the

transition to secondary school as a healthy challenge rather than a negative threat (Sirsch, 2003, p. 385) were strong predictors that students would successfully transition into secondary school (Curran Neild et al., 2008; Gillison et al., 2008; Jindal-Snape & Foggie, 2008; Newman et al., 2007; Rudolph et al., 2001; Seidman et al., 1994; Sirsch, 2003; Smith et al., 2008). Based on this study's findings, the data seem to suggest that transitional activities/planning were associated with their children reporting that they were "happy and liked" their school as they entered grade nine. However, formal IEP transitional planning, based on the findings of this study, appeared to replicate the previous body of research in which caregivers reported that students' IEP transitional plans were not adequately developed and implemented to facilitate their children's transition into and out of secondary school (Gelzheiser, McLane, Meyers, & Pruzek, 1998; Noland et al., 2007; Weber & Bennett, 2004). Interestingly, all six caregivers appeared to be unaware of the transitional plans that were required by law to be in place by the time their children were 14 years or over (Education Act, Reg. 181/98). Clearly, findings in this study appear to suggest that the limited transitional planning is a call for partnerships between school boards and agencies, such as Community Living. Agencies' who support families and their children with ID could be instrumental in partnering with the local Niagara school boards to assist students. Transitional planning would be enhanced by the "Individualized Lifestyle Planning (ILP)" facilitators approach to ensure self-identified goals are met with realistic action plans for facilitating those who could implement the successful transition of individuals with ID in and out of secondary school (Gosse, Griffiths, & Terreberry, 2008). ILP facilitators are individuals who provide support to groups of people who would come together with students with ID to plan their life goals. The process of planning is flexible, adaptable, and meaningful to the individual's personal goals across his/her life span. This type of planning would provide

students with ID who have dreams and career aspirations to realize some aspects of their hopes for the future.

Increasingly, professional supports/services for children with ID are moving towards models that place the caregivers as “experts” of their children (Minke & Anderson, 2005; Van Haren & Fiedler, 2008, p. 232). Caregivers of children with ID have often been cited as having to learn additional information about their children’s particular disabilities and have taken on various informal professional roles (e.g., medical, physiotherapist, speech pathologist, etc.) to provide services/supports that may not be covered by public funds or that they cannot afford to purchase (Minke & Anderson, 2005; Van Haren & Fiedler, 2008). Schools would benefit from adopting the “parent as the expert” approach that is presently published in the Ministry of Education documents pertaining to students with ID (2002, 2004) but appears to be sporadically put into practical application across the schools in Niagara based on the different experiences with schools caregivers reported in this study. The most compelling finding in this study that seem to suggest that empowering parents as the “experts” of their children would be beneficial for families with children who have ID (Van Haren & Fiedler, 2008, p. 232). The extent to which caregivers felt the emotional impact of their children’s social rejections and segregation provides a compelling argument for empowering caregivers in the transitional process. The dyadic complexities of their negative emotional outcomes were repeatedly evident throughout caregivers’ interviews, in which they reported that their children experienced social rejection but more so for the one student who had the greatest negative social and emotional outcome from his incongruent transitional experience.

Although the purpose of this research was to explore the role of educational inclusion during the transitional experiences of students with ID as they moved from elementary to

secondary school, the unique informed assent procedures used in this study warranted further reflection (see Appendix M). The successful outcomes and certain limitations of teaching informed assent to children with ID, along with the feasibility of researchers adopting this method for obtaining informed assent, are discussed in detail in Appendix M.

Chapter 5

Limitations and Implications

Limitations. The design of this research was purposive to explore an issue that has not been widely researched. Generalizability of the research findings was limited as the sample was too small for making inferences about the transitional experiences of the larger population of students with ID. As well, the study was qualitative; therefore inferences were excluded. Further, the results were limited to students with ID whose families were willing to volunteer, were able to communicate verbally during their interview and who were able to meet the informed assent criteria. However, the sample, albeit small, was sufficient to allow for a preliminary examination of important experiences during the transition to secondary school among students with ID.

Another limitation of this study involves recall bias, as participants were asked to retrospectively consider experiences related to the process of transitioning to secondary school. However, as discussed earlier, researchers who have examined the event of transitioning into secondary school characterize it as a major transition in an adolescent's life and this was observed to be associated with more salient memories of the event among the caregivers and their children with ID in this study (Gillison et al., 2008; Newman et al., 2007; Rudolph et al., 2001; Sabbatino & Macrine, 2007; Siedman et al., 1994; Sirsch, 2003; Smith et al., 2008). Further, data collection occurred while students were still in or just graduating from their secondary schools and thus appeared to increase the likelihood that participants were able to share their memories of their experiences.

Families' affiliations with Associations for Community Living may have been associated with a unique response bias. Community Living organizations are characterized by their vision and mission (Community Living Ontario, 2008), which promotes and advocates for educational

inclusion and equal opportunities for people with an ID. Future research should recruit participants with ID from a variety of sources to provide a more representative sample of students with ID. However, it was generally observed that caregivers were more inclined to support their children's needs rather than supersede their needs for being included in the regular classroom. In general, the data seem to suggest that inclusion was important to children's social development but was not considered absolutely necessary for their learning needs.

Comparisons between individual students were included to examine how transitional experiences of students with ID were similar to or different from those of their peers with ID who remained in segregated and inclusive educational settings. However, no comparison group was included for students without ID. Although this was a limitation, exclusion of peers without ID was purposive as they have often overshadowed the voices of students with ID in much of the research (Frazee, 2003). As well, in this study the possibility of pathologizing the experiences of students with ID was avoided by not comparing them to the experiences of students without ID. Alternately, the comparisons may as well "normalized" some of the transitional issues, especially social outcomes.

Implications. Knowing and defining how students with ID experience educational inclusion is a task usually assigned to administrators, educators, and internal review committees (Gelzheiser et al., 1998; Weber & Bennett, 2004). In contrast, this study provided an opportunity for students with ID to be included in the process of knowing and defining how they experienced transitioning to secondary school and the role of educational inclusion in that process and how it socially and emotionally affected them when they were included and/or excluded from full participation. As well, caregivers were included as "experts" of their children to assist with articulating the extent to which transitioning from elementary to secondary school affected their

children. As in this study, caregivers report being excluded from the process of planning and placement for their children's education (Weber & Bennet, 2004). Students with ID and caregivers took an active and what appeared to be an eager role in sharing their experiences of being included and/or excluded. The students in this study expressed their excitement for being included as participants in this study through their eagerness to answer my questions and in responses such as "this research, it's just amazing that you guys are letting me know and letting other kids know that there is a part of experience." Future research needs to provide individuals with ID and their caregivers the opportunity to directly participate. Innovative and creative methodologies (informed assent activities; see Appendices H and M) were discovered to be an effective method for providing some of the students in this study the chance to participate but further development of the tools are needed to adopt more inclusive methodologies to ensure that everyone with ID has equal opportunities to participate in research.

Chapter 6

Summary

Educational inclusion and the issues that are associated with educational inclusion are at the forefront of human rights research (Bach, 2002). Marginalization of one population based on their disability affects us all because everyone is dependent upon and needs each other to develop and grow (Anderson, 2006; Black, 1996). Research, such as this study, begins the exploration that is necessary to discover the complex layers associated with educational inclusion that includes those who experience it and are likely to be excluded because of their ID. Students with ID are the voices that are absent in much of the research that is for and about them, and this study provides these students the opportunity to actively share their experiences. The social philosophy of interdependence further underlies this study's shift from considering participants with ID as solely dependent and moves toward a model whereby everyone needs each other for informing and adding to the knowledge about educational inclusion. This study highlights how educational inclusion can potentially enhance the social and emotional development of people with and without ID in becoming humans and citizens in our diverse communities across Canada (Anderson, 2006).

Based on this study's findings, transition planning should be in place to assist students with ID and their caregivers before they make the transition to secondary school. This is particularly important for students who are anticipated to have incongruent transitional experiences from inclusive elementary to segregated secondary school environments. As well, this study's findings suggest that students with ID can benefit socially and emotionally from opportunities for inclusion, and that educational inclusion is not bounded to the traditionally imposed structure of the physical space of a regular classroom. Providing caregivers a role in

their children's transitional planning and experiences would assist in empowering families and with respecting caregivers as the "experts" of their children's needs (Van Haren & Fiedler, 2008, p. 232). The findings seem to suggest that caregiver involvement is an essential component of planning a successful transition to secondary school for students with ID. However, the findings also suggest that caregivers' love and protective natures towards their children needs to be mitigated by educating families about their children's rights and providing children with the tools they need for acting out their rights in social interactions. Unintentional compliance is a serious issue that, without rights training, may result in children with ID growing up learning as adults to be compliant rather than exerting their rights when faced with conflict or social rejection.

This study began the exploration that was necessary to discover the complex layers associated with educational inclusion that includes those who experience and those who are excluded from it because of having an ID. However, it is important to continue this line of research with a larger, randomized sample that would be more representative of the population of students with ID. A larger sample size would provide the opportunity for researchers to expand the transition model (see figure 1.1) to include a group of students without ID for drawing comparisons that were not possible in this study. A comparison group would assist with determining whether students' negative social and emotional outcomes from peer rejection were reasonable or unexpected. As well, a larger sample would provide the possibility for including a group that would represent the students who had incongruent transitional experiences from segregated elementary to inclusive secondary settings. Additionally, research in the future may consider expanding the transitional model (see figure 1.1) to extend beyond secondary school to examine how transitional experiences of students with ID are experienced as they prepare to

leave secondary school. Based on the findings of this research, it was found that the majority of caregivers reported their children had limited options after secondary school and keeping their children in secondary school until they were 21 seemed the logical response. However, based on this young adult's response – "Um the part that I don't like at this part in um, in being, in being at [school name] is just that I seem more older than most kids at the school". Future research needs to draw attention to these limited options and make recommendations for what students with ID would prefer as options for post-secondary opportunities.

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Appendix A: Community Living Agencies' Covering Letters

COMMUNITY LIVING

Welland Pelham



Our Vision: "AN INCLUSIVE CARING COMMUNITY WHERE ALL PEOPLE BELONG AND HAVE EQUAL OPPORTUNITY TO PARTICIPATE EFFECTIVELY"

Administrative Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: admin@communityliving.ca

Children's Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: children@communityliving.ca

Employment Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: employment@communityliving.ca

Family Support Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: family@communityliving.ca

Residential Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: residential@communityliving.ca

Volunteer Services

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: volunteer@communityliving.ca

Welland Packaging / Luggage Supports

325 Sutherland Avenue
Welland, ON L7R 4Y9
Tel: 905-736-9640
Fax: 905-736-9641
Email: packaging@communityliving.ca

Website

www.communityliving.ca

Barbara Vyrotsky, P.h.D., Executive Director
Community Living Welland Pelham
525 Sutherland Avenue
Welland, ON

Thursday, May 14, 2009

Dear Families:

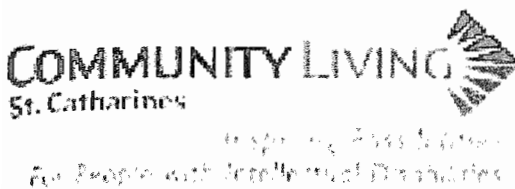
I am writing you to provide you information about an opportunity to be part of a research study that has been brought to our association's attention. The research is part of a Brock University graduate student's research study about educational inclusion. Educational inclusion continues to be an issue that many of our families with children who have intellectual disabilities advocate for and experience barriers/challenges. Although we are not directly involved with this specific study, I wanted to make sure our families were provided the opportunity to participate if they choose.

Enclosed is a letter that outlines the study and provides you with the opportunity to contact the graduate student, Marion Trent-Kratz, who is conducting the research study. I am forwarding this opportunity to you through the association to ensure that your family's confidentiality is maintained. If you choose to be part of the research study after reading the invitation letter, you are to contact Marion Trent-Kratz directly at her confidential phone number. Your choice to participate in the study is completely voluntary and your choice to participate or not will in no way impact the services or supports you receive from community living.

If you require more information about the study you should contact Marion Trent-Kratz directly at 905-736-9640.

Sincerely,

Barbara Vyrotsky



Administrative Offices

Al Moreland, Executive Director
Community Living St. Catharines
437 Welland Avenue
St. Catharines, ON

437 Welland Avenue
St. Catharines, Ontario
L2M 5V2
905-688-5222
Fax 905-688-9926
www.clscatharines.ca

Tuesday, March 10, 2009

Dear Families:

I am writing you to provide you information about an opportunity to be part of a research study that has been brought to our association's attention. The research is part of a Brock University graduate student's research study about educational inclusion. Educational inclusion continues to be an issue that many of our families with children who have intellectual disabilities advocate for and experience barriers/challenges. Although we are not directly involved with this specific study, I wanted to make sure our families were provided the opportunity to participate if they choose.

Enclosed is a letter that outlines the study and provides you with the opportunity to contact the graduate student, Marion Trent-Kratz, who is conducting the research study. I am forwarding this opportunity to you through the association to ensure that your family's confidentiality is maintained. If you choose to be part of the research study after reading the invitation letter, you are to contact Marion Trent-Kratz directly at her confidential phone number. Your choice to participate in the study is completely voluntary and your choice to participate or not will in no way impact the services or supports you receive from community living.

If you require more information about the study you should contact Marion Trent-Kratz directly at 905-736-9640.

Sincerely,

A handwritten signature in black ink, appearing to read "Al Moreland", is written over a horizontal line.

Al Moreland



Appendix B: Invitation Letter



**Brock
University**

Department of Child and Youth Studies
St. Catharines, Ontario, Canada L2S 3A1
T: 905-688-5550, Ext. 3710 F: 905-641-2509

www.brocku.ca

[Insert Date Letters were Sent]

Dear Families,

We are mailing you to tell you about a chance for your child to be part of a study that is about his/her experiences moving from primary school to high school and how they were included in his/her new school. Please read about my study below and if you are interested in taking part in the study, please contact Marion Trent-Kratz, Principal Investigator, at her private voicemail (905) 736-9640 and leave your name and phone number so that you may be contacted.

Title of Research Study: Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School

Principal Investigator: Marion Trent-Kratz, MA Candidate, Department of Child and Youth Studies, Brock University

Faculty Advisor: Christine, Tardif-Williams, Associate Professor, Department of Child and Youth Studies, Brock University

Marion Trent-Kratz, is a Graduate student from the Department of Child and Youth Studies, Brock University, and she is asking students with intellectual disabilities and their caregivers to be part of her study entitled Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School

The reason for this study is to give students with intellectual disabilities, who went to primary schools, the chance to share their experiences as they moved to high school. The goal of this study is to look at students' social and emotional experiences as they left primary school and entered high school.

Interviews are going to be conducted for this study and they will be scheduled from February to the end of June, 2009. Students and their caregivers who want to be part of the study will need to be able to set up two one hour interviews for their child and the caregiver to be interviewed separately. Children will be able to have his/her caregiver present during the interview if they express this desire. Choosing to be part of my study is voluntary and services/supports from Community Living are not part of this study and will not be impacted if you choose not to take part.

This research study should benefit students with intellectual disabilities because they have a chance to be part of a study that will give helpful information about a time in your child's

life and how he/she was affected. As well, your child will be given 1 in 20 chances (or more) to win an Apple Ipod Nano. It is 1 in 20 (or more) chances of winning as it will depend on the number of families who book an appointment to learn more details about the research study. Everyone who books an appointment will receive a ballot whether they take part in the study or not. If more than 20 potential participants book an appointment to learn more about the study, another Apple Ipod Nano will be given out with the same 1 in 20 (or more) chances of winning.

It is unlikely that your child or you will experience any harm or discomfort as a result of participation in an interview, however, uncomfortable or awkward moments may arise. If you or your child feels this way, you do not need to answer any questions that your child or you do not want to answer. You and your child can choose to leave the research study at any time, without penalty. As well, if your child shows that they are not interested in being interviewed, then they will be thanked for their part, given a ballot for the draw, and any information you and your child have provided up to that point will be destroyed and will not be included in the research study. Your Family Support Worker will be available to you and your child if he/she needs support. You and your child's privacy will be ensured with the use of made up names and his/her real identity will be kept separate from the data collected. Data collected during this research study will be kept for 5 years and stored in a locked filing cabinet in Christine Tardif-Williams' office at Brock University and copies of the data in electronic format will be stored on an usb memory stick kept in the locked filing cabinet. At the end of the 5 years all data will be shredded and electronically deleted. Only Christine Tardif-Williams, Faculty Supervisor, a research assistant, and Marion Trent-Kratz, researcher will have access to the data. Any disclosure of abuse, neglect, and threat or harm from others, to self or toward others or summons from a subpoena to testify will require a breach in confidentiality and have to be reported to Niagara Family and Children Services or Niagara Regional Police and you will be informed of the need to breach confidentiality in advance of your participation in this research study.

This research study is being done in partnership with two Community Living agencies in the Niagara Region.

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905- 688-5550 ext 3035, reb@brocku.ca)

If you have any questions about the research study, contact Marion Trent-Kratz or Dr. Christine Tardif-Williams at 905-688-5550 Ext. 4557 or by email at mt99ab@brocku.ca.

Thank you,

Marion Trent-Kratz
MA Candidate
905-688-5550 Ext. 4557
mt99ab@badger.ac.brocku.ca

Christine Tardif-Williams
Associate Professor, Faculty Supervisor
905-688-5550 Ext. 4557
ctardif@brocku.ca

This research study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 08-196]

Appendix C: Community Living Agencies' Support

COMMUNITY LIVING

Welland Pelham

"AN INCLUSIVE CARING COMMUNITY WHERE ALL PEOPLE BELONG
AND HAVE EQUAL OPPORTUNITY TO PARTICIPATE EFFECTIVELY"

Administrative Offices

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Children's Services

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Employment Services

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Family Support Services

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Residential Services

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Volunteer Services

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Welland Packaging / Leisure Supports

1000 Lakeshore Blvd. E.
Welland, ON L3B 5A4
Tel: 905-223-1111
Fax: 905-223-1112
www.communityliving.ca

Website

www.communityliving.ca

Barbara Vyrotsky, P.h.D.,
Executive Director
Community Living Welland Pelham
525 Sutherland Avenue
Welland, ON
L3B 5A4

Al Moreland, M.S.W.,
Executive Director
Community Living St. Catharines
437 Welland Avenue
St. Catharines, ON
L2M 5V2

December 9, 2008

RE: Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School Thesis Proposal

As Executive Directors of Community Living Welland Pelham and Community Living St. Catharines, we have reviewed and considered Marion Trent-Kratz's thesis proposal referred to above and we support her efforts in conducting her study. In supporting Marion, we have agreed to provide her access to our Family Support Services to facilitate the recruitment of participants for her proposed study.

Marion's research is of great interest to both of our associations as educational inclusion continues to be an issue that many of our families with children who have intellectual disabilities advocate for and experience barriers/challenges. We feel that Marion's proposal provides an inclusive and respectful approach as she is including individuals who are absent from much of the research for and about individuals with intellectual disabilities. Marion's methodological approach and sensitivity to the families we support is extremely valuable in her study. We feel that Marion's study will further inform our agencies about educational inclusion and it will help to build on the body of knowledge about educational inclusion of students with intellectual disabilities as they transition to secondary school.

If you require any further information, please contact us at the above address.

Sincerely,

Barbara Vyrotsky
Barbara Vyrotsky

Sincerely,

Al Moreland
Al Moreland

Appendix D: Family Support Workers' Follow Up Phone Script

[Insert Date of Phone Call]

Family Support Workers Phone Script for Follow-Up

Hi, [insert name], it [insert name] from Community Living calling. I am calling to find out if you had received a letter that was sent by mail inviting you and your child to participate in a research study being conducted by Marion Trent-Kratz, Child and Youth Studies graduate student. The purpose of this research study is to provide families and their children with intellectual disabilities the opportunity to be included in sharing their experiences as they left elementary school and started high school. The goal of this research study is to look at how children with intellectual disabilities are socially and emotionally affected as they moved from elementary to high school and the role of educational inclusion. The letter of invitation that you received in the mail provided you with the contact information for Marion Trent-Kratz at her confidential voicemail (905) 736-9640 if you are interested in being included in the study. You and your child's decision to participate will in no way affect your relationship with me or the supports/services I provide to you and your child through the association.

Appendix E: Appointment Form

[Insert Date Created]

Appointment Form

Code Identifier	Caregiver's Name & Child's Name	Address	Phone Number	Interview Location	Date & Time of Interview

Appendix F: Researcher Contact Phone Script

[Insert Date of Phone Contact]

Researcher Phone Script for Contacting Caregivers to Set Appointments

Hi, my name is Marion Trent-Kratz and I am calling from Brock University. I'm calling because you left your name and number since you are interested in finding out more information about my research study and possibly being a participant. Would you like to set up a date and time for myself and a researcher assistant, [Insert Name], to come and tell you more about the study? During our appointment, we will give you and your child more information about the purpose of the research study and the role you and your child would have if you are interested in participating. Once you have learned more about my study then you can decide whether you would like to participate. If you decide to participate, we can interview you and your child on that same day once you and your child have given us consent to do so. But if you decide that you and your child are not interested in participating after learning more about my study during our appointment then it will in no way affect your relationship with your family support worker or Community Living. So, would you like to book a time for an appointment? [If yes, go to second paragraph, if no; thank them for letting you contact them and inform them that you will not keep their contact information].

Are there times and dates between February 2nd and June 30th that would be convenient for you and your child to be provided more information about my study and if you are interested in participating after learning more about the study then you and your child could be interviewed that same day once you and your child have consented to do so. When you are considering a date and time it will have to be a day when you have at least 2 hours to set aside to allow you 1 hour and your child 1 hour to be interviewed if you and your child decide to participate after learning

more about my study. We are conducting the interviews separately so as to ensure you and your child's responses remain private; however, your child will have the option to have you present during his/her interview if they wish.

If it is okay with you can we go ahead and book the dates, times, and locations for you and your child's appointments? [If yes, proceed with script, if no; thank them for letting you contact them and inform them that you will not keep their contact information]. I will be recording the information on an appointment list and the information will be kept confidential from your family support worker and Community Living agency. For you and your child's appointments would you like us to come to your home or would you like to have you and your child's appointment at your Community Living agency.

If you decide that you and your child would like to cancel your appointment after speaking with me today, it will in no way affect your relationship with your family support worker or the support/services provided by Community Living and I will remove you and your child's name from the appointment list. [Record potential participants' information if they agree to an appointment, verbally confirm the date and time of their interviews and thank the caregivers].

Appendix G: Caregivers' Consent

Date: [Insert Date of Interview]

Project Title: Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School

Principal Investigator:

Marion Trent-Kratz, MA Candidate

Department of Child & Youth Studies

Brock University

905-688-5550 ext. 4557, mt99ab@brocku.ca

Faculty Advisor:

Christine Tardif-Williams, Associate Professor

Department of Child & Youth Studies

Brock University

(905) 688-5550 Ext. 4557

INVITATION

Your child and you are invited to participate in a study that involves research. The goal of this study is to give students with intellectual disabilities, who went to elementary schools, the chance to share their experiences as they moved to high school. The main goal of the study is to look at students' with intellectual disabilities social and emotional experiences as they were included in their new schools.

WHAT'S INVOLVED

As participants, your child and you will be asked to take part in one individual interview each that is about 60 minutes long. Interview dates and times will be set up when it is best for you and your child's schedules. During the interview your child and you will be asked to answer items on surveys and to share your child's Individual Education Transitional Plans. During the interview your child and you will be asked to share what the experience of going from elementary to high school was like.

Students and their caregivers who want to be part of the study will need to be able to set up two one hour interviews for their child and the caregiver to be interviewed separately. Children will be able to have his/her caregiver present during the interview if they express this desire.

Choosing to be part of my study is voluntary and services/supports from Community Living are not part of this study and will not be impacted if you choose not to take part.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the opportunity to participate in a research study that will provide helpful information about a time period in your child's life and how he/she was affected. As well, your child will have 1 in 20 chances (or more) to win an Apple Ipod Nano. It is 1 in 20 (or more) chances of winning based on the number of families who book an appointment to learn more about the research study. Everyone who books an appointment will get a ballot whether they take part in the study or not. If more than 20 families book an appointment to learn more about the study, another Apple Ipod Nano will be given out with the same 1 in 20 (or more) chances of winning. It is unlikely that your child or you will experience any harm or discomfort as a result of participation in an interview, however, uncomfortable or awkward moments may arise. If you or your child feels this way, you do not need to answer any questions that your child or you do not want to answer. You and your child can choose to leave the research study at any time, without penalty. Any information you have provided up to that point will be destroyed and will not be included in the research study. Additionally, your Family Support Worker will be available to you and your child if they need support.

CONFIDENTIALITY

You and your child's privacy will be ensured with the use of pseudonyms (codes) and his/her real identity will be kept separate from the data collected. Data collected during this research study will be kept for 5 years and stored in a locked filing cabinet in Christine Tardif-Williams' office at Brock University and copies of the data in electronic format will be stored on an usb memory stick kept in the locked filing cabinet. At the end of the 5 years all data will be shredded and electronically deleted. Only Christine Tardif-Williams, Faculty Supervisor, a research assistant, and Marion Trent-Kratz, researcher will have access to the data. Any disclosure of abuse, neglect, and threat or harm from others, to self or toward others or summons from a subpoena to testify will require a breach in confidentiality and have to be reported to Niagara Family and Children Services or Niagara Regional Police and you will be informed of the need to breach confidentiality in advance of your participation in this research study.

VOLUNTARY PARTICIPATION

You and your child's participation in this research study are voluntary. If you or your child wishes, he/she may decline to answer any questions or participate in any part of the research study. Further, you or your child may decide to withdraw from this research study at any time and may do so without any penalty and still receive a ballot for 1 in 20 chances (or more) to win an Apple Ipod Nano. It is 1 in 20 (or more) chances of winning based on the number of families who book an appointment to learn more about the research study. Everyone who books an appointment will get a ballot whether they take part in the study or not. If more than 20 families book an appointment to learn more about the study, another Apple Ipod Nano will be given out with the same 1 in 20 (or more) chances of winning. In no way will declining to participate affect your relationship with your Family Support Worker or the supports/services provided to you and your child from Community Living. Your child will be provided the opportunity to assent through a creative interactive activity to ensure they understand their rights to participate.

PUBLICATION OF RESULTS

Results of this research study will be available in printed format at Brock University Library and it may be published in professional journals, books, local Community Living agencies and presented at conferences. Invitations to attend the Community Living agency presentations will be sent to provide participants the opportunity to learn about what the research study found. Feedback about this research study will be available by emailing me at mt99ab@badger.ac.brocku.ca or by writing a request for information to Brock University, Child and Youth Studies, SB453, 500 Glenridge Avenue, St. Catharines, Ontario, L2S 3A1 or by phone at 905-688-5550 Ext. 4557.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this research study or require further information, please contact the Principal Investigator, Marion Trent-Kratz or the Faculty Advisor, Christine Tardif-Williams using the contact information provided above. This research study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (REB File: #08-196). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this research study.

CAREGIVERS CONSENT FORM

[Insert Date of Interview]

I agree to my child and I participating in this research study described above and I have explained this research study to my child and they understand the nature of his/her role in the research study and his/her right to voluntarily participate. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the research study and understand that I may ask questions in the future. My child and I understand that we may withdraw our consent at any time with no penalty and will receive a ballot for 1 in 20 chances (or more) to win an Apple Ipod Nano. It is 1 in 20 (or more) chances of winning based on the number of families who book an appointment to learn more about the research study. Everyone who books an appointment will get a ballot whether they take part in the study or not. If more than 20 families book an appointment to learn more about the study, another Apple Ipod Nano will be given out with the same 1 in 20 (or more) chances of winning.

Caregiver's Name (Print)

Caregiver's Signature

Date

Child's Name (Print)

In my opinion, the person who has signed above understands the nature of this research study and has agreed to their child and their participation in it is voluntarily.

Signature of researcher or witness

Appendix H: Children's Assent

[Insert Date of Interview]

Name of Lesson: Knowing All About Research

Subject:	Research and Informed Consent	Prepared By:	Marion Trent-Kratz
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Overview & Purpose:	Interactive and fun activities with concrete materials will be used to teach students with intellectual disabilities and their caregivers about research and informed consent/assent. At the end of the activities, students with intellectual disabilities and their caregivers should understand what research means; know what it means to give consent/assent, and to be a participant in a research study.
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Stages of Learning	Researcher's Guide	Materials/Resources
Objectives (Skills/information that will be learned)	<ol style="list-style-type: none"> 1. Know what research means 2. Know what it means to get permission to collect data (information) 3. Know about collecting data: <ol style="list-style-type: none"> a. Know what it means to get informed consent/assent b. Know how data is collected and why 4. Know how to report on data 	Materials Needed <ul style="list-style-type: none"> ▪ Stick'm Chart ▪ Paper ▪ Variety of Coloured Markers ▪ Blind Fold ▪ Miniature Toy Animals ▪ Opaque Cups ▪ "Animals in the Zoo" (Allan Fowler, 2000)

Activities (To reinforce the lesson)	<ol style="list-style-type: none"> 1. Introduce the book to student by showing him/her the cover and tell them the title. 2. Ask student what they think the book is about. 3. Ask the student if they have been to the zoo before (if yes, ask him/her what he/she saw at the zoo, if no, ask him/her if he/she might go in the future). 4. Ask student what his/her favourite animal is? 5. Ask student if they would like to have the book read aloud (if yes, then read, if no, then ask him/her if he/she would like to stop; if yes, then thank student and give draw ballot, if no, then ask him/her if you can read story; if students answers no again, then thank them for his/her time and give draw ballot). 6. Read book aloud to student. 7. Ask student if they enjoyed the book. 8. Ask the student if they want to do an activity about the book (if yes, go to step 9.; if no, then thank them for participating and give draw ballot). 9. Tell the student that we are going to do some “research” about the book and explain that it means we are going to gather some information (“data”), talk about how we will collect the “data”, and report the “data”. 10. Before the student starts the activity ask the student if the animals that we will put on the list know if we are talking and writing about them and discuss how the animals should give us the “okay” for us to use their information. 11. Discuss how important it is that the animals give us permission to gather information about them and report on it because it would not be right for us to do it without them knowing and agreeing. 12. Talk about how giving permission to know about someone is the same when you gather information about “humans”. 13. Line up toy animals and place cups over them. 14. Ask student if he/she knows which animals are under the cups and talk about how it is important that the animals in our “research” have their privacy. 15. Discuss how privacy means that no-one would be able to match what we learn about the animals in the zoo to any one animal. 16. Ask the research assistant to put a blind fold on and then remove the cups from the toy animals and ask the research assistant if he/she can point to where the lion is. Discuss with the student why the research assistant is unable to find the lion because he/she is “blind” and cannot identify the animals. 17. Relate this back to how it is important in research that no one person can be identified and that “special” code numbers or names can be used to keep people or animals true identity private. 18. Use chart paper and markers and let the student/caregiver hold the book – Ask the student to name the different types of animals he/she remembers from the book and record his/her responses on the chart paper. 19. Assign each animal a code letter and number (e.g. A1).
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Verification (Steps to check for student understanding)	<ol style="list-style-type: none"> 20. Add up the number of animals on the chart paper by counting them one-at-a-time with student aloud. 21. Ask student if there is one animal that they like most. 22. Ask student if there might be an animal that they would leave out of the list. 23. Ask student to group animals by colour, size, male/female, etc. 24. When the list is completed ask the student if there is anything else about the book that they would like to write on the chart paper. 25. Ask the student what they thought of gathering information and about keeping the animals "true" identity private. 26. Discuss with the student how the same precautions must be done with research that is done with human beings but it is even more important to keep people's identity private. 27. Discuss with student how maybe one or two of the animals might not want to be on our list and how it is okay if they do not want to be part of the list because they have the "right" to do what they want to do. 28. Relate the freedom to leave the list to humans having the "right" to do what they want to do and if they do not want to be in a study or want to leave a study they are free to do so just like the animals that wanted to leave our list. 29. Ask the student if they have any questions about the activities. 30. Ask the student if they are interested in hearing more about my study and move onto verification activity. <p>Read the assent/consent aloud to student and relate the information in the letter to what they learned about research.</p> <p>To ensure the student understands their rights to assent to participate they must answer yes to the following questions to be included in the research study:</p> <ol style="list-style-type: none"> 1. If you do not want to be part of the research study is it okay? (Circle One) <div style="display: flex; justify-content: space-around; width: 100%;"> YES NO </div> 2. Is it okay for you to decide at any time during the research study to not have a part in some or all of the research study? (Circle One) <div style="display: flex; justify-content: space-around; width: 100%;"> YES NO </div> 3. Do you know for sure that your part in the research study will be private and no one will know who you are from the information collected? (Circle One) <div style="display: flex; justify-content: space-around; width: 100%;"> YES NO </div> <p>If all 3 have YES circled, proceed with interview. If there are No's circled, debrief participant and thank them for their participation, and help them to fill out a ballot for the draw.</p>
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MINOR ASSENT FORM

[Insert Date of Interview]

I want to participate in this research study because I know what the research study is about and I know what I will be asked to do in the research study. I have learned that I have the right to freely take part in the research study. I want to take part because of what I learned about research. I have been able to ask questions about the research study and know that I may ask questions at any time in the future. I also learned and know that I may leave the research study at any time with no penalty and will receive a ballot for 1 in 20 chances (or more) to win an Apple Ipod Nano. It is 1 in 20 (or more) chances of winning based on the number of families who book an appointment to learn more about the research study. Everyone who books an appointment will get a ballot whether they take part in the study or not. If more than 20 families book an appointment to learn more about the study, another Apple Ipod Nano will be given out with the same 1 in 20 (or more) chances of winning.

Child's Name (Print)

Child's Signature

Date

In my opinion, the person who has signed above understands the nature of this research study and has agreed to their child and their participation in it is voluntarily.

Signature of researcher or witness

Appendix I: Draw Ballots

[Insert Date Created]

Ballots for Draw to Win Apple Ipod Nano

Win an Apple Ipod Nano

Name:

Phone Number:

Date of draw is to take place on the 30 of June, 2009. Only the winner will be contacted and arrangements will be made to deliver the Apple Ipod Nano when it is convenient for the winner.

Win an Apple Ipod Nano

Name:

Phone Number:

Date of draw is to take place on the 30 of June, 2009. Only the winner will be contacted and arrangements will be made to deliver the Apple Ipod Nano when it is convenient for the winner.

Appendix J: Confidentiality Agreement

[Insert Date Created]

Confidentiality Agreement

This agreement is made the _____ day of _____, 2009

Research Study Title: Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School

[Insert name and address of other party]

Recitals

- A. One or both of the above parties possesses confidential information which it wishes to disclose to the other party so that the confidential information can be used to conduct the above mentioned research study.
- B. To enable the research study to take place and to protect the rights of existing in and in relation to that information, the parties now desire to enter this Agreement.

It is Agreed that:

1. Scope of Information

The confidential information to be disclosed and subject to this agreement is in relation to the research study title outlined above.

2. Obligation of Confidence

The parties to this Agreement agree that all such confidential information whether in the form of data, reports, models, samples, and regardless of how communicated or recorded, received by either of them from the other party is confidential and proprietary and will be kept as such. They shall take such steps as are necessary to ensure that they safeguard information as outlined in the data collection procedures for this research study.

3. Use and Restriction on use

The recipient of the confidential information shall use all the confidential information in confidence solely for the purpose of the research study stated above. The recipient shall not –

- a) make any other use of the confidential information except as expressly authorized by the disclosing party in writing; and
- b) disclose or permit or cause to be disclosed the confidential information to any persons except the principle researcher and thesis advisor.

4. Exceptions

The obligations of confidentiality shall not apply to any confidential information disclosed to either party to the extent that it –

- a) is likely to result in harm or abuse to participants or others and requires parties to report suspected harm to Family and Children Services or Niagara Regional Police;

5. No Rights Conferred

No confidential information disclosed to recipients provides the party rights to ownership of that information during data collection for the research study and no right to use the confidential information unless specifically provided the right in writing by the principal researcher.

6. Confidential Information

All data will be collected, transcribed, and safe guarded immediately following each interview and stored as soon as possible at Brock University, Christine Tardif-Williams' Office in a locked cabinet. No data should reside with parties unless it is being used to conduct and report on the research study.

7. Duration

This Agreement shall terminate five years from its date of signature.

Signature

Date

Name Printed

Position

Appendix K: Measures

[Insert Date of Interview]

Participants' Code

Caregiver's Interview Guide

Go over the information letter/consent form with participants and have them sign the consent form. After signing...Thank you for agreeing to share some of your thoughts about [insert child's name] experiences as they left elementary school to attend high school. I am trying to see how changing schools may socially and emotionally affect students with intellectual disabilities and how they were included in their new school. So I will be asking you some questions for you to comment about how changing schools and being included affected [insert child's name]. Remember if you do not want to answer any questions or you want to leave the study at any time you are free to and you and your child's interview will be deleted and not used in the final report.

School History

Name of high school: _____ Current grade: _____

Number of children in class: _____

Was the child ever held back to repeat a grade? No Yes, which grade(s): _____

Is the child in special education: No Yes, beginning when: _____

If the child receives special education, how many hours of service does the child receive per week? (e.g. pull-out, separate classroom)

Was your child in special education in elementary school (Circle One) Yes No

If yes, how many hours of service did the child receive per week?

Does the child: (Circle One)

Have problems getting along with other children in class? Yes No

Have problems making friends in school? Yes No

Have problems getting along with teachers? Yes No

Tend to get sick in the morning before school? (e.g. headache, stomach ache, etc.)? Yes No

What subject (s) does your child find most challenging at school?

What is your child's favourite subject at school?

c) What does educational inclusion mean to you?

1. Probe: How important is it to you that [insert child's name] is placed in a regular classroom?
2. Probe: Why?
3. Probe: Does [insert child's name] attend the same classes as other students without intellectual disabilities?
 - i. Probe: If yes, which ones?
 - ii. Probe: If no, why?

Administer CBCL/6-18 (Achenbach, 2001a) and use as points for discussion and to ask questions to probe.

- iii. Probe: How was [insert child's name] behaviour different from when they were in grade 8?
- iv. Probe: In what way are [insert child's name] friendships different than when they were in elementary school?
 1. Probe: Does he/she have more friends than when they were in elementary school?
 - a. If yes, why?
 - b. If no, why?
4. Are there times when [insert child's name] does not want to go to school?
 - i. Probe: Can you explain or give an example of when [insert child's name] may have not wanted to go to school?
 - ii. Probe: What might be some of the reasons [insert child's name] he wanted to avoid going to school?
5. Are there times when [insert child's name] enjoys going to school?
 - i. Probe: Can you explain or give an example of when [insert child's name] had a great day at high school over the past 5 months?

Thank you for participating.



Please print **CHILD BEHAVIOR CHECKLIST FOR AGES 6-18**

For office use only
ID # _____

CHILD'S FULL NAME First _____ Middle _____ Last _____			PARENTS' USUAL TYPE OF WORK, even if not working now. (Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, telephone operator, shoe salesman, army sergeant.)	
CHILD'S GENDER <input type="checkbox"/> Boy <input type="checkbox"/> Girl	CHILD'S AGE _____	CHILD'S ETHNIC GROUP OR RACE _____	FATHER'S TYPE OF WORK _____	
TODAY'S DATE Mo. _____ Date _____ Yr. _____			MOTHER'S TYPE OF WORK _____	
CHILD'S BIRTHDATE Mo. _____ Date _____ Yr. _____			THIS FORM FILLED OUT BY: (print your full name) _____	
GRADE IN SCHOOL _____	Please fill out this form to reflect your view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. Be sure to answer all items.		Your gender: <input type="checkbox"/> Male <input type="checkbox"/> Female	
NOT ATTENDING SCHOOL <input type="checkbox"/>			Your relation to the child: <input type="checkbox"/> Biological Parent <input type="checkbox"/> Step Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Adoptive Parent <input type="checkbox"/> Foster Parent <input type="checkbox"/> Other (specify) _____	

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc. <input type="checkbox"/> None	Compared to others of the same age, about how much time does he/she spend in each? Less Than Average Average More Than Average Don't Know	Compared to others of the same age, how well does he/she do each one? Below Average Average Above Average Don't Know
a. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
b. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
c. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, computers, singing, etc. (Do not include listening to radio or TV.) <input type="checkbox"/> None	Compared to others of the same age, about how much time does he/she spend in each? Less Than Average Average More Than Average Don't Know	Compared to others of the same age, how well does he/she do each one? Below Average Average Above Average Don't Know
a. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
b. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
c. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
III. Please list any organizations, clubs, teams, or groups your child belongs to. <input type="checkbox"/> None	Compared to others of the same age, how active is he/she in each? Less Active Average More Active Don't Know	
a. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
b. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
c. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.) <input type="checkbox"/> None	Compared to others of the same age, how well does he/she carry them out? Below Average Average Above Average Don't Know	
a. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
b. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
c. _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Be sure you answered all items. Then go other side.

Please print. Be sure to answer all items.

1. About how many close friends does your child have? (Do not include brothers & sisters)

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours?

(Do not include brothers & sisters)

☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Has no brothers or sisters
b. Get along with other kids?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c. Behave with his/her parents?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d. Play and work alone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

3. 1. Performance in academic subjects.

☐ Does not attend school because _____

Check a box for each subject that child takes

other academic subjects—for example: computer courses, foreign language, business. Do not include gym, shop, driver's ed., or other nonacademic subjects.

	Failing	Below Average	Average	Above Average
a. Reading, English, or Language Arts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. History or Social Studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Arithmetic or Math	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Does your child receive special education or remedial services or attend a special class or special school?

☐ No ☐ Yes—kind of services, class, or school:3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe:

When did these problems start? _____

Have these problems ended? ☐ No ☐ Yes—when? _____Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child.

Please print. Be sure to answer all items.

Below is a list of items that describe children and youths. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know)		1 = Somewhat or Sometimes True	2 = Very True or Often True
0	1	2	1. Acts too young for his/her age
0	1	2	2. Drinks alcohol without parents' approval (describe): _____
0	1	2	3. Argues a lot
0	1	2	4. Falls to finish things he/she starts
0	1	2	5. There is very little he/she enjoys
0	1	2	6. Bowel movements outside toilet
0	1	2	7. Bragging, boasting
0	1	2	8. Can't concentrate, can't pay attention for long
0	1	2	9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
0	1	2	10. Can't sit still, restless, or hyperactive
0	1	2	11. Clings to adults or too dependent
0	1	2	12. Complains of loneliness
0	1	2	13. Confused or seems to be in a fog
0	1	2	14. Cries a lot
0	1	2	15. Cruel to animals
0	1	2	16. Cruelty, bullying, or meanness to others
0	1	2	17. Daydreams or gets lost in his/her thoughts
0	1	2	18. Deliberately harms self or attempts suicide
0	1	2	19. Demands a lot of attention
0	1	2	20. Destroys his/her own things
0	1	2	21. Destroys things belonging to his/her family or others
0	1	2	22. Disobedient at home
0	1	2	23. Disobedient at school
0	1	2	24. Doesn't eat well
0	1	2	25. Doesn't get along with other kids
0	1	2	26. Doesn't seem to feel guilty after misbehaving
0	1	2	27. Easily jealous
0	1	2	28. Breaks rules at home, school, or elsewhere
0	1	2	29. Fears certain animals, situations, or places, other than school (describe): _____
0	1	2	30. Fears going to school
0	1	2	31. Fears he/she might think or do something bad
0	1	2	32. Feels he/she has to be perfect
0	1	2	33. Feels or complains that no one loves him/her
0	1	2	34. Feels others are out to get him/her
0	1	2	35. Feels worthless or inferior
0	1	2	36. Gets hurt a lot, accident-prone
0	1	2	37. Gets in many fights
0	1	2	38. Gets teased a lot
0	1	2	39. Hangs around with others who get in trouble
0	1	2	40. Hears sounds or voices that aren't there (describe): _____
0	1	2	41. Impulsive or acts without thinking
0	1	2	42. Would rather be alone than with others
0	1	2	43. Lying or cheating
0	1	2	44. Bites fingernails
0	1	2	45. Nervous, highstrung, or tense
0	1	2	46. Nervous movements or twitching (describe): _____
0	1	2	47. Nightmares
0	1	2	48. Not liked by other kids
0	1	2	49. Constipated, doesn't move bowels
0	1	2	50. Too fearful or anxious
0	1	2	51. Feels dizzy or lightheaded
0	1	2	52. Feels too guilty
0	1	2	53. Overeating
0	1	2	54. Overlired without good reason
0	1	2	55. Overweight
0	1	2	56. Physical problems without known medical cause:
0	1	2	a. Aches or pains (not stomach or headaches)
0	1	2	b. Headaches
0	1	2	c. Nauseas, feels sick
0	1	2	d. Problems with eyes (not if corrected by glasses) (describe): _____
0	1	2	e. Rashes or other skin problems
0	1	2	f. Stomachaches
0	1	2	g. Vomiting, throwing up
0	1	2	h. Other (describe): _____

Please print. Be sure to answer all items.

0 = Not True (as far as you know)

1 = Somewhat or Sometimes True

2 = Very True or Often True

1	2	57. Physically attacks people	0	1	2	84. Strange behavior (describe): _____
1	2	58. Picks nose, skin, or other parts of body (describe): _____	0	1	2	85. Strange ideas (describe): _____
1	2	59. Plays with own sex parts in public	0	1	2	86. Stubborn, sulky, or irritable
1	2	60. Plays with own sex parts too much	0	1	2	87. Sudden changes in mood or feelings
1	2	61. Poor school work	0	1	2	88. Sulks a lot
1	2	62. Poorly coordinated or clumsy	0	1	2	89. Suspicious
1	2	63. Prefers being with older kids	0	1	2	90. Swearing or obscene language
1	2	64. Prefers being with younger kids	0	1	2	91. Talks about killing self
1	2	65. Refuses to talk	0	1	2	92. Talks or walks in sleep (describe): _____
1	2	66. Repeats certain acts over and over; compulsions (describe): _____	0	1	2	93. Talks too much
1	2	67. Runs away from home	0	1	2	94. Teases a lot
1	2	68. Screams a lot	0	1	2	95. Temper tantrums or hot temper
1	2	69. Secretive, keeps things to self	0	1	2	96. Thinks about sex too much
1	2	70. Sees things that aren't there (describe): _____	0	1	2	97. Threatens people
1	2	71. Self-conscious or easily embarrassed	0	1	2	98. Thumb-sucking
1	2	72. Sets fires	0	1	2	99. Smokes, chews, or sniffs tobacco
1	2	73. Sexual problems (describe): _____	0	1	2	100. Trouble sleeping (describe): _____
1	2	74. Showing off or clowning	0	1	2	101. Truancy, skips school
1	2	75. Too shy or timid	0	1	2	102. Underactive, slow moving, or lacks energy
1	2	76. Sleeps less than most kids	0	1	2	103. Unhappy, sad, or depressed
1	2	77. Sleeps more than most kids during day and/or night (describe): _____	0	1	2	104. Unusually loud
1	2	78. Inattentive or easily distracted	0	1	2	105. Uses drugs for nonmedical purposes (don't include alcohol or tobacco) (describe): _____
1	2	79. Speech problem (describe): _____	0	1	2	106. Vandalism
1	2	80. Stares blankly	0	1	2	107. Wets self during the day
1	2	81. Steals at home	0	1	2	108. Wets the bed
1	2	82. Steals outside the home	0	1	2	109. Whining
1	2	83. Stores up too many things he/she doesn't need (describe): _____	0	1	2	110. Wishes to be of opposite sex
			0	1	2	111. Withdrawn, doesn't get involved with others
			0	1	2	112. Worries
			0	1	2	113. Please write in any problems your child has that were not listed above:
			0	1	2	_____
			0	1	2	_____
			0	1	2	_____

Individual Educational Plan: Transition Plan Form

[Insert Date of Interview and Participants' Code]

Transition Plan

Student's name _____ GEN/MIN _____

Specific Goal(s) for Transition to Postsecondary Activities

Actions Required	Person(s) Responsible for Actions	Timelines

6

5

Children's with ID Interview Guide

[Insert Date of Interview]

Participants' Code

Go over the information letter/assent activities with participants and ask them the questions that they must say "yes" to demonstrate that they understand that they are free to participate.

Thank you for letting me ask you a few questions about school. The questions I am going to ask are about going to high school and what it is like for you. I am also going to ask you about when you were in grade 8. I am trying to put together information to see what it is like for you to go from grade 8 to grade 9. Remember the activities we did before we started this interview and how you are free to not answer any question that you are not comfortable sharing the answers with me or you can choose to leave the research study and your information will not be used in the research study. Do you have any questions before we start?

1. Throughout the interview use items from the YSR (Achenbach, 2001c) to probe for discussion.

(Ask these at item

2. Is there anything about school you do not like?
 - i. Probe: Why?
3. What is your favourite thing about going to school?
 - i. Probe: Why?



Please print

YOUTH SELF-REPORT FOR AGES 11-18

For office use only
ID # _____
☒ FULL NAME _____

First _____

Middle _____

Last _____

☐ Boy ☐ Girl

YOUR GENDER

YOUR AGE

YOUR ETHNIC GROUP
OR RACE
☐ Boy ☐ Girl

COMPARISON DATE

Date _____

Yr. _____

Mo. _____

Day _____

Yr. _____

☐ NOT ATTENDING SCHOOL ☐ ATTENDING SCHOOL

 IF YOU ARE WORKING, PLEASE STATE YOUR TYPE OF WORK: _____

 PARENTS' USUAL TYPE OF WORK, even if not working now. (Please be specific — for example, auto mechanic, high school teacher, homemaker, lawyer, airline operator, stock salesman, army sergeant.)
 FATHER'S TYPE OF WORK: _____
 MOTHER'S TYPE OF WORK: _____

Please fill out this form to reflect your views, even if other people might not agree. Feel free to print additional comments beside each item and in the spaces provided on pages 2 and 4. Be sure to answer all items.

1. Please list the sports you most like to take part in. For example: swimming, basketball, skating, skate boarding, bike riding, fishing, etc.

Compared to others of your age, about how much time do you spend in each?

Compared to others of your age, how well do you do each one?

☐ None

a. _____

Less Than Average

☐

More Than Average

☐

Below Average

☐

Above Average

b. _____

☐
☐
☐
☐
☐
☐
☐

c. _____

☐
☐
☐
☐
☐
☐
☐

2. Please list your favorite hobbies, activities, and games, other than sports. For example: cards, books, piano, cars, computers, crafts, etc. (Do not include listening to radio or watching TV.)

☐ None

a. _____

Less Than Average

☐

More Than Average

☐

Below Average

☐

Above Average

b. _____

☐
☐
☐
☐
☐
☐
☐

c. _____

☐
☐
☐
☐
☐
☐
☐

3. Please list any organizations, clubs, teams, or groups you belong to.

Compared to others of your age, how active are you in each?

☐ None

a. _____

Less Active

☐

More Active

☐
☐
☐
☐

b. _____

☐
☐
☐
☐
☐
☐
☐

c. _____

☐
☐
☐
☐
☐
☐
☐

4. Please list any jobs or chores you have. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

a. _____

Below Average

☐

Above Average

☐
☐
☐
☐

b. _____

☐
☐
☐
☐
☐
☐
☐

c. _____

☐
☐
☐
☐
☐
☐
☐

Be sure you answered all items. Then see other side.

Please print. Be sure to answer all items.

V. 1. About how many close friends do you have? (Do not include brothers & sisters)

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week do you do things with any friends outside of regular school hours?

(Do not include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

3. Compared to others of your age, how well do you:

	Worse	Average	Better	
a. Get along with your brothers & sisters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> I have no brothers or sisters
b. Get along with other kids?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c. Get along with your parents?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d. Do things by yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

II. 1. Performance in academic subjects.

☐ I do not attend school because _____

Check a box for each subject that you take	Falling	Below Average	Average	Above Average
a. English or Language Arts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. History or Social Studies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Arithmetic or Math	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any illness, disability, or handicap? ☐ No

☐ Yes—please describe:

Please describe any concerns or problems you have about school:

Probably what do you like about school?
What do you not like about school?

Please describe any other concerns you have:

Please describe the best things about yourself:

Please print. Be sure to answer all items.

Below is a list of items that describe kids. For each item that describes you *now* or *within the past 6 months*, please circle the number that is *very true* or *often true* of you. Circle the 1 if the item is *somewhat* or *sometimes* true of you. If the item is *not true* of you, circle the 0.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very True or Often True

1	2	1	I feel too young for my age	0	1	2	33. I feel that no one loves me
1	2	2.	I drink alcohol without my parents' approval (describe): _____	0	1	2	34. I feel that others are out to get me
1	2	3	I argue a lot	0	1	2	35. I feel worthless or inferior
1	2	4.	I fail to finish things that I start	0	1	2	36. I accidentally get hurt a lot
1	2	5.	There is very little that I enjoy	0	1	2	37. I get in many fights
1	2	6.	I like animals	0	1	2	38. I get teased a lot
1	2	7.	I brag	0	1	2	39. I hang around with kids who get in trouble
1	2	8.	I have trouble concentrating or paying attention	0	1	2	40. I hear sounds or voices that other people think aren't there (describe): _____
1	2	9.	I can't get my mind off certain thoughts; (describe): _____	0	1	2	41. I act without stopping to think
1	2	10.	I have trouble sitting still	0	1	2	42. I would rather be alone than with others
1	2	11.	I'm too dependent on adults	0	1	2	43. I lie or cheat
1	2	12.	I feel lonely	0	1	2	44. I bite my fingernails
1	2	13.	I feel confused or in a fog	0	1	2	45. I am nervous or tense
1	2	14.	I cry a lot	0	1	2	46. Parts of my body twitch or make nervous movements (describe): _____
1	2	15.	I am pretty honest				
1	2	16.	I am mean to others				
1	2	17.	I daydream a lot	0	1	2	47. I have nightmares
1	2	18.	I deliberately try to hurt or kill myself	0	1	2	48. I am not liked by other kids
1	2	19.	I try to get a lot of attention	0	1	2	49. I can do certain things better than most kids
1	2	20.	I destroy my own things	0	1	2	50. I am too fearful or anxious
1	2	21.	I destroy things belonging to others	0	1	2	51. I feel dizzy or lightheaded
1	2	22.	I disobey my parents	0	1	2	52. I feel too guilty
1	2	23.	I disobey at school	0	1	2	53. I eat too much
1	2	24.	I don't eat as well as I should	0	1	2	54. I feel overtired without good reason
1	2	25.	I don't get along with other kids	0	1	2	55. I am overweight
1	2	26.	I don't feel guilty after doing something I shouldn't				56. Physical problems without known medical cause:
1	2	27.	I am jealous of others	0	1	2	a. Aches or pains (not stomach or headaches)
1	2	28.	I break rules at home, school, or elsewhere	0	1	2	b. Headaches
1	2	29.	I am afraid of certain animals, situations, or places, other than school (describe): _____	0	1	2	c. Nausea, feel sick
1	2	30.	I am afraid of going to school	0	1	2	d. Problems with eyes (not if corrected by glasses) (describe): _____
1	2	31.	I am afraid I might think or do something bad	0	1	2	e. Rashes or other skin problems
1	2	32.	I feel that I have to be perfect	0	1	2	f. Stomachaches
				0	1	2	g. Vomiting, throwing up
				0	1	2	h. Other (describe): _____

Please print. Be sure to answer all items.

0 = Not True

1 = Somewhat or Sometimes True

2 = Very True or Often True

- 1 2 57. I physically attack people
- 1 2 58. I pick my skin or other parts of my body (describe): _____
- 1 2 59. I can be pretty friendly
- 1 2 60. I like to try new things
- 1 2 61. My school work is poor
- 1 2 62. I am poorly coordinated or clumsy
- 1 2 63. I would rather be with older kids than kids my own age
- 1 2 64. I would rather be with younger kids than kids my own age
- 1 2 65. I refuse to talk
- 1 2 66. I repeat certain acts over and over (describe): _____
- 1 2 67. I run away from home
- 1 2 68. I scream a lot
- 1 2 69. I am secretive or keep things to myself
- 1 2 70. I see things that other people think aren't there (describe): _____
- 1 2 71. I am self-conscious or easily embarrassed
- 1 2 72. I set fires
- 1 2 73. I can work well with my hands
- 1 2 74. I show off or clown
- 1 2 75. I am too shy or timid
- 1 2 76. I sleep less than most kids
- 1 2 77. I sleep more than most kids during day and/or night (describe): _____
- 1 2 78. I am inattentive or easily distracted
- 1 2 79. I have a speech problem (describe): _____
- 1 2 80. I stand up for my rights
- 1 2 81. I steal at home
- 1 2 82. I steal from places other than home
- 1 2 83. I store up too many things I don't need (describe): _____

- 0 1 2 84. I do things other people think are strange (describe): _____
- 0 1 2 85. I have thoughts that other people would think are strange (describe): _____
- 0 1 2 86. I am stubborn
- 0 1 2 87. My moods or feelings change suddenly
- 0 1 2 88. I enjoy being with people
- 0 1 2 89. I am suspicious
- 0 1 2 90. I swear or use dirty language
- 0 1 2 91. I think about killing myself
- 0 1 2 92. I like to make others laugh
- 0 1 2 93. I talk too much
- 0 1 2 94. I tease others a lot
- 0 1 2 95. I have a hot temper
- 0 1 2 96. I think about sex too much
- 0 1 2 97. I threaten to hurt people
- 0 1 2 98. I like to help others
- 0 1 2 99. I smoke, chew, or sniff tobacco
- 0 1 2 100. I have trouble sleeping (describe): _____
- 0 1 2 101. I cut classes or skip school
- 0 1 2 102. I don't have much energy
- 0 1 2 103. I am unhappy, sad, or depressed
- 0 1 2 104. I am louder than other kids
- 0 1 2 105. I use drugs for nonmedical purposes (don't include alcohol or tobacco) (describe): _____
- 0 1 2 106. I like to be fair to others
- 0 1 2 107. I enjoy a good joke
- 0 1 2 108. I like to take life easy
- 0 1 2 109. I try to help other people when I can
- 0 1 2 110. I wish I were of the opposite sex
- 0 1 2 111. I keep from getting involved with others
- 0 1 2 112. I worry a lot

Please be sure you answered all items.

Please write down anything else that describes your feelings, behavior, or interests:

Appendix: L: Qualitized CBCL/16-18 and YSR Items and Responses

CBCL/16-18 and YSR Items and Responses

CBCL/6-18. (Items from measure bolded)

Researcher: So did you find when she went from grade 8 to 9 that she might've complained a bit about being **lonely**? Not having as many friends, or?

P4: Um, do I remember the, I don't remember her saying that. No. Wait a minute. I do remember her saying that she noticed that she wasn't able to talk to the other, like her grade 8 friends. Like that's what she missed a bit because you know, you go from a, you know she was in a class with like, I don't know what, 30 kids that she knew. That she had gone all the way through with, then you go into a high school where there's all kinds of, you know, you're spread out all over the place. So that part she would say, oh she wishes she could talk to them and they might not be as attentive.

C4: I still don't know why some of them wouldn't talk to me.

YSR. (Items from measure bolded)

Researcher: ...So um did you find when you left grade 8 um and now went into grade 9, did you find that you had a lot of emotions around that, or **mood changes** or feelings about, that would just suddenly change that you know, I really like this, or I don't like this?

C3: Just feelings. From being bullied going into grade 9, I just thought that I was crying, like you know, like when I was being bullied, they'd kick my shins. And being followed around every step behind, I'd hear my name, they'd kick my shoes. But you know, in grade 9, I, there was none of that. 'Cause having, high

school has a very high tolerance for bullying. And I kind of thought, this, this, this is the school for me.

It is apparent from these examples that opportunities to probe were provided based on the caregivers' and their children's responses to the items from both measures. One item from the measures typically resulted in rich in-depth data. These two measures were specifically chosen because of their focus on young students' social and emotional outcomes (Achenbach, 1999/2001a/2001b).

Appendix M: Informed Assent Process

Informed Assent Process of Students with ID and Discussion

A lesson plan was developed (see Appendix H) to teach what ‘research’ means and what ‘voluntary’ assent means. An animal book (“Animals in the Zoo” by Allan Fowler, 2000) and Plain Language about research in a zoo was used to teach students with ID about the process of doing research. The book contained realistic photographs of animals and children with ID benefitting from the concrete examples in this book as they learned about research and their role in the research. In this study, chart paper and markers were used to record what the children had learned about research and it was reviewed before they engaged in the activities to demonstrate their understanding about their rights to participate. Questions were used to determine children’s level of understanding about informed assent and voluntary participation. In this study, the children were required to demonstrate a thorough understanding of informed assent and their rights to participate voluntarily, using questions and activities that were developed in detail in a lesson plan in Appendix H. Thorough understanding was determined by participants’ ability to perform the activities correctly and answer “yes” to all the questions at the end of the activity. In this study, five of seven children were able to demonstrate their understanding of assent to participate. Of the two that assent was not obtained, one did not want to participate and one was unable to demonstrate his understanding of assent. Children’s understanding of assent was determined by 100% accuracy in responding to the following questions using *yes* after having been taught about research and their role in the research:

1. If you do not want to be part of the research study is it okay?
2. Is it okay for you to decide at any time during the research study to not have a part in some or all of the research study?

3. Do you know for sure that your part in the research study will be private and no one will know who you are from the information collected?

In some circumstances the language (e.g., private) in the above questions had to be explained to some of the children. After children had said “yes” to all three questions, the children’s interviews proceeded. When one child had said “yes” in response to the questions above but it was because he was mimicking or repeating what the researcher was saying his caregiver and him were debriefed and thanked for their participation; they also filled out a ballot for the draw.

The informed assent process was effective for determining 5 out of the 6 students’ understanding of their participation in the research and their capacity to voluntarily participate. The success for meeting the informed assent criteria was demonstrated by 5 out of 6 students. The level of functioning and the student’s capacity to communicate were issues that resulted in two of the five students requiring additional review of the material presented, the use of Plain Language, and the assistance of these students’ caregivers. One of the five was unable to meet the assent criteria despite efforts to use his Picture Exchange System (PECS) to communicate with him.

Adopting more inclusive methodologies for gaining informed assent would have provided the one student with ID the opportunity to participate in the research (Cameron & Murphy, 2006). More inclusive methodologies would have included increasing the time for the informed assent process, developing assent tools that included pictures/images to overcome language barriers, and perhaps using body language (a willingness to sit with the researcher and the assistant, seeking contact with the researcher and her assistant, providing answers during the caregiver’s interview) could have been interpreted as a willingness to participate; however, understanding what it means to participate would still need to be determined concerning this one

participants' involvement in the study. Cameron and Murphy (2006) suggest that caregivers' consent should have sufficed in circumstances when informed assent criteria were not met; however, it could be argued that more inclusive methodologies would have resulted in obtaining informed assent. Inclusive methodologies would have provided this student with the opportunity to be an active participant rather than a passive participant that was complying to participate based on his/her caregivers' consent to participate. Increasingly, researchers should explore methodological options/tools that would provide individuals with ID more active roles in the research so that their voices are included in the process of forming the knowledge for them and about them.

Appendix N: REB Approval Letter



DATE: February 11, 2009
FROM: Michelle McGinn, Chair
Research Ethics Board (REB)
TO: Christine Tardif-Williams, Child and Youth Studies
Marion Edna Trent-Kratz
FILE: 08-196 TARDIF-WILLIAMS
Masters Thesis/Project

TITLE: Examining the Inclusion Experiences of Students with Intellectual Disabilities: A Study Focusing on the Transition from Elementary to Secondary School

The Brock University Research Ethics Board has reviewed the above research proposal.

DECISION: Accepted as Clarified (with note)

Please Note:

The phrasing "1 in 20 chances or less" does not accurately reflect your plan to give away one iPod for every 20 participating families. The odds are 1 in 20 (or better).

This project has received ethics clearance for the period of February 11, 2009 to July 31, 2009 subject to full REB ratification at the Research Ethics Board's next scheduled meeting. The clearance period may be extended upon request. ***The study may now proceed.***

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and cleared by the REB. During the course of research no deviations from, or changes to, the protocol, recruitment, or consent form may be initiated without prior written clearance from the REB. The Board must provide clearance for any modifications before they can be implemented. If you wish to modify your research project, please refer to <http://www.brocku.ca/researchservices/forms> to complete the appropriate form Revision or Modification to an Ongoing Application.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is required for all projects upon completion of the project. Researchers with projects lasting more than one year are required to submit a Continuing Review Report annually. The Office of Research Services will contact you when this form *Continuing Review/Final Report* is required.

Please quote your REB file number on all future correspondence.

MM/kw

Research Ethics Office
Brock University Office of Research Services, MC D250A
500 Glenridge Avenue, St. Catharines, ON L2S 3A1
phone: (905)688-5550, ext. 3035

fax: (905)688-0748

email: reb@brocku.ca

http://www.brocku.ca/researchservices/Ethics_Safety/Humans/Index.php